Through the Window: Creativity as a Tool for Family Members Caring for a Loved-One Living with Dementia.

by © Megan Morrison

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Abstract

This study provides first-hand arts-informed narratives from caregivers at locations in St. John's and rural Newfoundland. The narratives draw attention to the creativity involved in providing care to a family member with dementia by exploring the less visible aspects of the caregiving role and illustrate that caregivers attend to personhood through creativity. The objective of the research was to provide a deeper understanding of the caregiving role through exhibiting participants' creative projects at a community venue. The study took place in St. John's, NL Canada between 2012 and 2014. Twelve family caregivers shared their caregiving story through an initial meeting, a creative project, and an art exhibit. The participants engaged with symbol, metaphor, imagery, and text to share their narratives using song-writing, singing, home renovation, photography, painting, poetry, short story, film, pencil-sketch, geo-caching, felted-wool, digital story, mixed media, and play-dough. The artifacts created by the participants helped the participants to articulate their caregiving roles and the often invisible work they do. This study found that caring for a family member who is living with dementia is essentially a creative solution-finding role. In looking at these family caregivers through a creative lens, one can see otherwise invisible aspects of their lives. This research contributes to how we understand the context of caring for a loved one with dementia.

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Table of Contents

Table of Plates

Chapter 1
Introduction

Sometimes a creative person can take a situation and shift it into something new, different and better. (Annie)

It is bringing together things to make a brand new thing. Whether it be a thing, a method of coping, or a way of helping, or dealing with your life. (Luke)

Creating the window, for the most part, was fun and rewarding. The most difficult was recalling what I have lost through this terrible disease. Maybe I will realize later that it was therapy for me. (Ren)

There is no way to quantify the hours that family caregivers provide for their loved ones living with dementia because many aspects of their labour are invisible to the outside world and thus have been absent in much of the literature. Invisible labour involves the contemplative and emotional spaces behind the observable actions. Thoughts and feelings are not visible, but a person can communicate them through the creative arts. In terms of emotional supports for family caregivers, there are few options outside of community-based support groups. These support groups have a valuable role for many people; however, there is a need to express and share knowledge and experience in other ways as well.

An estimated 564,000 people in Canada are currently living with dementia (CIHI, 2018). The number of people living with dementia is expected to rise to 937,000 by the year 2031 (2018). What these numbers also reveal is the number of people providing care for persons living with dementia. The Canadian Institute for Health Information reported that in 2013/2014, the prevalence of dementia in seniors 65 and older was 3.4% of the population in Newfoundland and Labrador. There is a need for additional research into how family members navigate caring for a loved one with dementia as the number of people afflicted in our communities continues to grow.

The literature shows that caregiving for a family member living with dementia is different from other types of care-relationships. The Canadian Institute for Health Information states that family caregivers spend more hours providing care and live with higher stress levels than those caring for seniors without dementia (2018). There are massive expectations on family members to provide care to loved ones living with dementia. There is limited research on how these caregivers strive to meet these expectations and how creativity plays a role in their daily lives. One of the reasons this is important is that the relationship role-specific supports may be a valuable tool to support family members caring for a loved one living with dementia. Beyond the daily activities of living and the maintenance of the relationship, family caregivers are attending to issues of personhood. Definitions of personhood vary in different fields, but in the context of dementia, many scholars use Kitwood (1997)'s definition which states that it is "[a] standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (P.8). This definition aligns with the research objectives of the current study as I explore how family members attend to these concepts. It is vital to consider personhood beyond the individual living with dementia, as they live in a social world, and the ways that family members provide care exist within a social context as well. Leibing and Cohen (2006) state that "[p]ersonhood, in general refers to the person within – the reflexive, immaterial, communicable essence of a person that is located deep within the body, but that is sometimes veiled by symptoms" (p.243). Research exploring personhood from a professional care perspective leads one to wonder how family caregivers are attending to the same needs without specific guidance/support.

Throughout this paper, I refer to "visible" and "invisible" spaces of care. I chose these words over others (for example "hidden" and "revealed") because they allow for a somewhat neutral discussion around the significance of care. The invisible component of many acts of care is the emotion exchange. This research is necessary because it highlights the need for further supports for individuals caring for a loved one with dementia that acknowledges their strengths and their capacity to care beyond what current literature conveys. Family members tend to their loved ones in the dementia context in unique and creative ways, and this study helps make the extent of that care visible.

To understand how family caregivers tend to and navigate these spaces, we must first understand the needs of the person living with dementia. Kitwood (1997) articulates that there are five essential needs to feel loved: comfort, inclusion, identity, occupation, and attachment. Best practice for professional care providers is a person-centred approach because it recognizes the person living with dementia and their needs. However, how family members attend to these needs remains largely unexplored. We know that the caregiving journey is challenging for family members. In general the supports extended to informal caregivers include time away or "respite". There is little support to direct or support family caregivers from a creative perspective. The lack of support is because the depth of care and creativity remains invisible to the outside community and sometimes to the caregivers themselves. There is not a lot known about how caregivers use their creativity in everyday life (Bellass et al., 2018). The role of everyday creativity for family caregivers requires further study in the context of dementia: “no study has documented the underlying thought processes and strategies when dealing with a relative with dementia” (Cheng, Mak, Lau, Ng, & Lam, 2015, p. 458).

1.1 Positioning Creativity

There is no singular definition of creativity that suits all contexts. Research shows that coming up with a standard definition for creativity can be a challenge (Kerr, 2009; Hall & Thomson, 2018). The following definition helps to situate creativity in a general sense so that a more nuanced discussion of creativity in this research can follow:

> …creativity is the ability to transcend traditional ideas, rules, patterns, or relationships to create significant new ideas, forms, methods, or interpretations. Creativity is sometimes also known as originality, progressiveness, or imagination. It is used in various domains, from science and technology to history and the arts; it is employed by experts, everyday people, and even children. It is used to solve problems or as a form of personal expression (Kerr, 2009, p.424).

McNiff (2015) theorizes that “…creativity is a defining quality of the human spirit”. Runco (2004) states that creativity is about determining what the challenge is, as much as it is about finding the solution. Each individual’s unique creativity is “…manifested in the intentions and motivation to transform the objective world into original interpretations, coupled with the ability to decide when this is useful and when it is not” (Runco, 1996, p.4). Runco uses the term “creativity” as an adjective to move away from the assumption that a person must produce something in order to be creative. He suggests that there are many avenues where one can apply “creative” as a descriptor in addition to art form. These avenues include “creative performance, creative potential, creative behaviour, creative personality, creative products and so on” (2004, p.28). In this paper, I define creativity as a concept that engages people in finding meaning out of everyday practice through symbol and metaphor. Everyday creativity is even more challenging to define. Kerr (2009) suggests that equating art with creativity limits everyday creativity and “casts a shadow on everyday expressions of creativity” (2009, p.337). Creativity and meaning-making exist along a continuum (2009). Recognizing and valuing everyday creativity is important because “…everyone has creative capacity – necessary for coping with uncertainty, daily problem solving, and sometimes even survival. The expression of everyday creativity also has the potential to result in a healthier, happier, and more meaningful life experience” (2009, p.338).

Creativity is more than a skill to create art, and it is a skill that enables people to develop solutions that fit their unique situation. In developing these solutions, individuals also reap the benefits of the creative process. That said, creativity is meaningful or beneficial even when it is not recognized or guided by others. McFadden and Basting (2010) state that “[c]reative engagement differs from the activities that take place in art, music, and dance therapy because its goal is not the amelioration of psychological or physical symptoms and it does not rely on the participation of a professional therapist (p.151). On the surface, the benefit is finding a way to deal with change (central in living with dementia). McNiff (2015) asserts that creativity is not about planning and predicting, but about dealing with the moment. Creativity is a useful tool for caregivers because providing care for a loved one with dementia is also about unpredictable and unplanned moments (Verkaik et al., 2016). It is essential to understand how family members adapt and respond to change in order to understand how to support them in their role (2016). Defining everyday creativity is in a way, also defining invisible spaces of caregiving. As the reader moves through this paper they will find examples of everyday creativity in the caregivers' stories.

Creativity is an asset that is inherent in human beings, but it can also be encouraged to develop and grow through recognition and practice. McNiff (2015) emphasizes that "…creative expression happens when we immerse ourselves in a process trusting it will shape and lead" (para.35). This process is engaged when confronted with change. McNiff also states that "…artistic expressions offer a tangible resource for understanding the nature of creative action, which is broader in scope and applicable to any sphere of life focused on change and imagination" (2015, para.9). It is important to distinguish between creative process and artistic process as the mechanism behind both is creativity, and in this research, participants engage with both. In this research creativity is revealed in family members' everyday adaptations to change in their loved one living with dementia, and it is also engaged in artistic expression as family members share the meaning behind these adaptations. The exhibit is essentially a merge between the two creative processes. Family members reveal their innate creativity through their artistic process, and the result is a creative process that allows others to recognize the multiple meanings of caring for a loved one with dementia.

Fostering the creative process has a positive effect on health and well-being. There is much evidence within community health research, specifically within arts and health research and also in research on creative arts therapies that there is direct benefit from participating in an artistic process for persons living with dementia. Young, Camic, and Tischler (2016) state that, "[d]ating back to the eighteenth century, it has been widely believed that the arts had the potential to have positive effects morally, emotionally and spiritually. More recently, recommendations have been made that arts interventions are a necessary part of health care provision and are considered to have benefits for health and well-being…" (p.337). There is also growing evidence to support the benefit of both caregivers and their family members participating in the arts. This study is the first of its kind in how I approach both the creative process within caregiving and the creative expression of meaning in that process through artistic artifact.

In this thesis, the reader will come across creativity as an everyday tool used to navigate caring for a loved one with dementia, as a method for participants to reflect on these spaces, and as an opportunity to share their creativity with a community audience. This study aims to give family members caring for a loved one with dementia an opportunity to reflect and share their stories. This study's objective is to demonstrate that creativity has a vital role in helping family members navigate their care role, in building awareness of their strengths and skills, and in connecting with those around them. This research addressed the question: How do family caregivers use everyday creativity in the context of dementia? The following are the objectives that seek to address the research question:

- Identify everyday creativity in contexts where a family member is caring for a loved one with dementia.

- Explore possible representations of caregivers’ experiences through metaphor, imagery, sound, and symbols.
- Present caregiving experiences in an exhibit of individual creative projects with arts-informed representations.
- Examine the overall findings on everyday creativity and invisible spaces of caring for a family member living with dementia.

It is essential to define creativity in the context of family members providing care to a loved one with dementia to engage with the participants’ contributions and see the significance of this research. In the context of caring for a person with dementia, creativity is relational (Bellass et al., 2018). Creativity is part of how caregivers attend to the needs within the relationship, whether their own needs or the needs of the person with dementia. Bellass et al. (2018) explain that everyday creativity can be both instrumental and non-instrumental. In the context of caring for a family member with dementia, this means that creativity can address a goal or it can arise out of an appreciation for creativity in general. All types of creativity are valuable, both within the context of caregiving and in terms of contribution to this study. In this study, one will see examples of family members’ creativity in response to a need, as well as spontaneous creativity. Everyday creativity occurs in joyful situations as well as those that are difficult (Bellass et al., 2018). The value of creativity is that it encourages people to interact with the moment at hand (Hayes, 2011). The power of this understanding of creativity as part of the everyday is that it will allow us to see creative family caregiving spaces that are not often visible. Hayes illustrates the mechanism behind this process,

> [s]omething from deep inside us pours out, unfiltered by culturally influenced self-consciousness. We make contact with something *essential* in our being. From this point of contact in ourselves we reach out to the *essential* in others, nurturing deep living relationship with them (p. 31).

In this study, I explore the caregiving experience through a methodology that creatively facilitates an arts-informed space for family caregivers, allowing them to explore their narrative, make meaningful connections with their creativity, and share an artistic representation of such with the community.

Arts-informed research allows engagement with participant knowledge in multiple ways. In this research, I engaged knowledge as a text with many different forms. I engaged with the participants first in an initial interview. Following the interview and transcription/read-through of their stories, we then met a second time to discuss individual creative projects. For the second meeting, I brought a transcript of the initial interview with highlighted themes and stories that stood out to me. Together, each participant and I looked at the themes and talked about what was meaningful to them and what they felt would be meaningful for others. The participants created these projects while reflecting on symbols, metaphors, and imagery that were meaningful to them. Each individual expressed that they were ready to begin their creative project at our second meeting. The participants were given an open-ended time frame to complete their projects. The participants informed the level of communication between us. In some instances, I was asked to check back with them in two weeks and in others, I waited for them to call and provide an update. The participants' creative projects were exhibited in a community venue to highlight their creativity in the caregiving role and lend visibility to otherwise unseen care spaces.

The exhibit included song-writing, singing, home renovation, photography, painting, poetry, short story, film, pencil-sketch, geo-caching, felted-wool, digital story, mixed media, and play-dough. This study contributes to what we know about providing care to a loved one living with dementia by revealing that creativity is at the core of navigating care. The value of bringing artistic process into the mold is that "…it gives us the idea of art as a way of seeing (or hearing, etc.) that goes beyond the everyday life" (Hughes & McCormack, 2014, p.203). Hughes & McCormack draw this conclusion from Wittgenstein (1980) who suggested that "[a] work of art forces us – as one might say – to see it in the right perspective but, in the absence of art, the object is just a fragment of nature like any other…" (pp 4-5). If one applies this theory not only to object, but to creativity in the everyday, then in this study's context, each family member has the authority to decide what is meaningful from their perspective.

I organized this thesis into seven chapters. In Chapter 1 (Introduction), I provide an introductory context to the research question, the research issue, the objectives of this project, and the chosen methods to address the objectives, as well as an overview of the thesis' organization. Chapter 2 (Literature Review) is a critical engagement with the literature, including a discussion of dementia, the family caregiving role, and recent studies engaging with family caregivers in creative ways. Chapter 3 (Methodology) describes and justifies my use of qualitative methodologies, specifically arts-informed methodology. Chapter 4 (Caregivers) is where the reader meets the participants and receives an introduction to their lives and their creativity. Chapter 5 (The Exhibit) is a tour of the participants' creative projects in a community arts and research exhibit which includes professional photographs to document the event. Chapter 6 (The Pieces We Have Come to See) is a discussion of the research findings. Finally, Chapter 7 (Reflections) brings the entire thesis together to analyze the contribution of my study, explore further research potential, and acknowledge limitations.

Chapter 2
Literature Review

2.1 Introduction

The literature review serves an important purpose. It provides a foundation for the reader to understand how the study fits in the current field and, most importantly, what it contributes. This chapter is a set of tools to help the reader fully embrace the participants' process, caregiving context, and contribution to understanding how family members use creativity in everyday caregiving for a loved one living with dementia. The first section is an overview of dementia and its effect on the individual living with it. This context will also help the reader to understand how dementia can affect family members. The second part introduces the caregiving space. In other words, I explore how the literature explains what is involved in the family caregiver role. In this thesis, I use the concept of space as a synonym to context. I explore and analyze how the literature explains caregiving and which elements of caring are not often noticed by those outside the home. Finally, I look at what person-centred care brings to our understanding of the family caregiving role and what still needs further exploration in the field.

The caregiving literature uses various terminology to denote a family member caring for a loved one with dementia: family/familial, informal, non-professional, and unpaid caregiver. I use the term family caregiver because it implies a previous relationship between caregiver and care receiver and thus some degree of emotional connection. The terms informal, non-professional, and unpaid caregiver have different connotations as they draw attention to what is lacking or "less than" in comparison to a professional caregiver, and this can encourage “disempowering narratives” (Milligan & Wiles, 2010). The term “family caregiver” draws attention to unique and compelling narratives constructed around this role. Family caregivers are unique because their role (and the work within it) is often invisible to the outside community and sometimes even to other family members outside the home. The invisibility occurs because family members are more likely to consider much of their role as part of their responsibility within the relationship and part of their familial role (White et al., 2018). This chapter provides a starting point for the current study so the reader can see how the participants’ contributions deepen our understanding of how family members experience caring for a loved one with dementia.

2.2 Dementia and Dementia-Care Needs

Dementia became an issue of public concern in the 1970s (Ballenger, 2017). Ballenger (2017) suggests that it was common to institutionalize people living with dementia. Katzman, a neurologist, played a crucial role in attributing dementia to Alzheimer’s disease rather than to normal ageing (Katzman, 2004). The link discovered between dementia and Alzheimer’s disease allowed researchers and clinicians to focus on its pathology and treatment (Ballenger, 2017). Advocates in the 1980s rallied for caregivers to receive recognition and support for their role and to change the stigma associated with dementia (Ballenger, 2017). Stigma has a tremendous impact on how we understand dementia and how individuals experience the caregiving role. Studies show that stigma around dementia exists as a barrier to family members’ emotional health and well-being (Neugaard, Andresen, McKune, & Jamoom, 2008; Post, 2000). Swinnen and

Schweda (2015) point to the connection between stigma and well-being. These authors state that,

> [u]nderstanding the multiple ways by which dementia, while biologically influenced, is at the same time culturally constructed contributes to the fight against stigma and can improve the wellbeing of people with dementia and their caregivers (p.11).

Family members who choose not to let others know that their loved one lives with dementia are often providing care in isolation. Being isolated may also mean the caregiver does not receive support. McIntyre (2003) highlights that "[i]nformation and images about how Alzheimer's disease interrupts the narrative of ''normal'' ageing tend to emphasize loss— of memory, of capabilities, of relationships, of self" (p. 482). The stigma associated with dementia has historical roots. A biomedical model has heavily influenced perceptions of dementia as an inevitable decline of cognitive abilities (O'Connor et al., 2007). Boller and Forbes (1998) assert that, in ancient Egypt, society pointed to anyone with dementia-like symptoms as having a "disorder". Philosophers such as Plato and Horatius suggested that old age and mental illness went hand in hand (Boller & Forbes, 1998). These authors illustrate that in the Hellenistic period, clinicians used "acute" and "chronic" to distinguish between mental illnesses where there was a possibility of reversal or not. This distinction was a step towards defining the symptoms of dementia. These perceptions are problematic, as both the individual living with dementia and their caregiver feel the effects of stigma. In the last decade of the second century (AD), perceptions of dementia evolved, and there was more distinction between normal ageing and mental illness (Boller & Forbes, 1998).

After the work of the 1700s and 1800s, stronger definitions of dementia started to emerge (Boller & Forbes, 1998). The DSM IV defined dementia as "a loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning" (Boller & Forbes, 1998). Current literature suggests a significant movement towards recognizing the personhood of the individual living with dementia. Dementia can be defined as a syndrome associated with multiple neurodegenerative disorders and is commonly associated with memory loss (Korczyn et al., 2012). Although dementia's most common association is with Alzheimer's disease, other conditions that cause dementia include vascular dementia, Lewy body dementia, frontotemporal dementia, and dementia in Down syndrome (Smale & Dupuis, 2004). Gale, Acar and Daffner (2018) state that, "[d]ementia is any decline in cognition that is significant enough to interfere with independent, daily functioning. Dementia is best characterized as a symptom rather than as one particular disease" (p.1161). While there are varying degrees of progression and impact with each type, all types of dementia impact cognitive function. At present, there is no cure for these brain diseases. As Korczyn et al. suggest, "[d]ue to the fact that the brain is already considerable damaged by the time full-blown dementia is detected, attempts to capture patients with minimal cognitive impairment, have led to the introduction of broader terms, including mild cognitive impairment" (p.2). In this thesis, I discuss dementia as a broad term (although at times participants refer to specific medical conditions), because it emphasizes the significance of considering the full spectrum of care experience before and beyond any diagnosis.

The progression of dementia is an integral part of understanding the person with dementia's care needs and how they fluctuate over time (Mitchell & Agnelli, 2015). Impact on cognition is a clinical commonality that carries across each type of dementia. The clinical field describes dementia as diminished mental capacity, possible changes in personality, inability to maintain language/communication, and increasing loss of memory (Mitchell & Agnelli, 2015). Extensive research exists on how dementia manifests in a clinical sense throughout the stages. However, there is less research on how individuals experience advanced dementia as their ability to access language diminishes (O'Connor et al., 2007). We know that in the earliest stage of dementia, an individual can retain much independence in day-to-day activities even though the earliest symptoms involve memory loss. For a time, dementia can go unnoticed because some memory loss is a symptom associated with normal ageing. A small amount of memory loss may not prevent an individual from maintaining an independent lifestyle (Steeman, Dierckx de Casterle, Godderis, & Grypdonck, 2006). As dementia progresses, memory loss increases and becomes complicated by other cognitive symptoms. The individual's family is more likely to notice symptoms during the middle stage where confusion and frustration add to memory loss, and basic daily activities become more challenging for the individual (Steeman et al., 2006). Late-stage dementia involves increased difficulty for the person in most areas of day-to-day life with an additional impact on physical abilities (Davies, Maio, Rait, & Iliffe, 2014). A person in this stage has lost the capacity to maintain their own needs and are now relying on others for care (Davies et al., 2014).

There are also significant implications for an individual's relationship with themselves, their friends and family and their community.

In many cases, dementia can diminish an individual's coping skills (Kitwood, 1997). When coping mechanisms (for example, anxiety, endurance, and self-control) are removed, different personality traits may emerge (Kitwood, 1997). As dementia symptoms progress, a person's care needs and the role of their caregiver also increases. However, this is not a linear progression. Types of dementia symptoms, the magnitude of their presence, and their sequence all vary from person to person. Also, there is no predictable timeline. For example, one person may live with one or two symptoms, and they may not intensify for several years, whereas for another person's symptoms may be intense and progress quickly within a shorter period.

Behavioural and psychological symptoms can come and go for periods as long as six months, which means that care needs will fluctuate back and forth as well (Kales, Gitline, Lyketsos, 2015). Kales et al. (2015) state that "[a]lthough cognitive symptoms are the hallmark of dementia, behavioural and psychological symptoms often dominate both the presentation and course of disease, creating the most difficulties for people with dementia, their carers, and providers" (Kales et al., 2015, p. 2).

The experience of living with dementia goes beyond stages, symptoms and cognitive changes. Research indicates that the type of care an individual receives can reduce or soften more challenging dementia symptoms (Kitwood, 1997). Steeman et al. (2006) suggest that to understand lived experience in the context of dementia, we have to move past treating the disease (2006). Labelling a person with dementia as “declining” draws attention to everything a person has lost. There is growing research showing that despite what is lost, a person with dementia is still able to have positive experiences (Alpert & Womble, 2015; Cohen, 2002; Hughes, 2015).

In many cases, family caregivers are equipped to enable these positive experiences, as they know the individual with dementia on an emotional level. While burden is a reality for many caregivers (Etters, Goodall & Harrison, 2008) existing literature overemphasizes the “burden” aspect of care. There is growing evidence to support that family members have positive experiences while providing care to a loved one living with dementia. However, the field is still relatively new, and additional research will help us to understand how these experiences are initiated (Wolverson, Clarke & Moniz-Cook, 2016). Further research into the positive aspects of caregiving will help to remove the stigma attached to dementia, strengthen person-centred approaches, and consequently strengthen opportunities for caregivers to experience their role and the relationship more positively (Wolverson et al., 2016). As Autio and Rissannen (2018) suggest, caring for a family member living with dementia presents a “challenging life situation which at best can support personal growth, if the processing of both positive and negative emotions is included in daily life” (p. 45). Processing caregiving emotions in the context of dementia is a task that can build and strengthen creative skills such as “distress buffering, mediation in coping with stress, increased quality of life and wellbeing, and finding a sense of purpose” (Autio & Rissannen, 2018, p. 45). This study asks the reader to consider family caregivers’ strengths and creativity while they navigate a challenging space.

2.3 Caring for a Family Member Living with Dementia

To understand the meanings attributed to caring for a loved one with dementia, one also needs to know how caregiving is different for family members (in comparison to friends, neighbours, or paid care). It is crucial to get a sense of where the role begins, how it progresses, and the impact on the experience. La Fontaine and Oyebode (2014) state that family relationships directly impact and are impacted by well-being. Often, the child or spouse is the family member that takes on the caregiver role (CIHI, 2018; Novais, Dauphinot, Krolak-Salmon & Mouchoux, 2017). Multiple factors influence this decision, including gendered expectations, pre-existing relationship, cultural expectations, and living proximity (Cavaye, 2008). Milligan and Wiles (2010) suggest, "the decision to give care, and who provides it, can be based on a wide range of factors including need, close kinship bonds, norms and values around gender and kinship, ability to cope, proximity, labour and employment relations, the availability and cost of alternative sources of support, and financial and opportunity costs" (p. 738). Multiple variables shape the caregiving experience, including demographics, type/symptoms/timeline of dementia, an existing relationship, caregiver's personality, the experience of the role and coping strategies (Brodaty & Donkin, 2009). In this study, I address caregiver variables concerning change. In the context of dementia, change can be as slight as putting an extra ingredient in a soup or it can be completely forgetting a recipe that has been made countless times. The emotional and social impact also varies. Depending on the relationship and the symbol meanings and/or interpretation of behaviours, the response to a person forgetting a recipe, for example, will have different meanings. Verkaik et al. (2016) state that “[m]anaging changes in the behaviour and mood of their relative with dementia is stressful for family caregivers because of constantly having to switch, continuously having to keep the person with dementia occupied and distracted, the fact that others see a different side to the relative, and the fact that caregivers know what to do, but are often not able to put this into practice (p.2). These responsibilities can have a direct impact on the caregiver’s social and family well-being. Some changes may simply mean finding a new way to do something and others may mean grieving the loss of a tradition, a symbol of love, or major component of their loved-one’s identity. Several authors focus on how the partnership in a marriage is affected by the caregiving role (Hayes et al., 2009; Hellström, Nolan, & Lundh, 2007; Davies & Gregory, 2007; Sherrell, Buckwalter, & Morhardt, 2001). Other variables that affect one’s caregiving experience include “patient-related factors, socio-demographic variables, effects of kinship status, [and] culture and ethnicity” (Sharma, Chakrabarti, & Grover, 2016, p. 7). The variables are essential in considering how family members (both care provider and receiver) shift within their relationship to provide care to a loved one living with dementia. The previous relationship and the expectations of each person shift in the context of the relationship and while some care spaces are revealed (visible) others remain hidden (invisible).

2.4 Visible and Invisible Spaces of Care

Caregiving is more than everyday tasks, and there are also spaces in between and surrounding tasks that involve creative thinking and adapting to change before what is needed is fully determined. An invisible space is one not yet discovered or recognized.

To understand “invisible” spaces in caring for a loved one living with dementia, I first discuss the visible aspects. The visible aspects of care have a significant presence in the literature. Milligan & Wiles (2010)’s discussion of “caring for” vs. “caring about” highlights some of what I consider to be the difference between visible and invisible care. These authors state that there is much crossover between caring for and about (Milligan & Wiles, 2010; see also: Graham, 1991). When a caregiver is “caring for” their family member, they are engaged in a performance of activities that are required (Milligan & Wiles, 2010). “Caring for” is defined as more intense involvement than what their previous relationship would have entailed (Milligan & Wiles, 2010; see also: Twigg & Atkin, 1994). Even if an individual is not physically or emotionally close to the person with dementia, “caring for” is more than what would be involved in the prior relationship (Milligan & Wiles, 2010). The act of “caring about” requires an emotional proximity to be close regardless of physical proximity (Milligan & Wiles, 2010). “Caring about” is a role that is embodied and characterized as “being caring” (Milligan & Wiles, 2010). There are also instances where the two aspects of caring (about and for) cross over. For example, a family member will often care both “for” and “about” a person. Family caregivers then, find ways to “support [their loved one] with encouragement, personal attention, and communication in ways that endorse a *mutual* sense of identity and self-worth” (p. 736). This research highlights the need to ask different questions and in different ways. While the research shows that caring for a loved one with dementia is complex, there is a need for additional research into how this complexity manifests, and in what way we can make the depth of the caregiving role visible.

Visible aspects of caregiving include what is visible to those outside of the dyad. Jansson, Nordberg and Grafström (2001) highlight that invisible care is when family members perform caregiving activities quietly inside the family. Jansson et al. (2001) observed family members providing care within the home. Their findings are a combination of visible and invisible care; however, they are tasks performed in a specific time and space. They found four broad themes and categories under each theme to depict the activities associated with the family caregiving role: activities of daily living (hygiene/dressing-undressing, meals/medicine), communication (communication, empathy/thoughtfulness, nearness), supervision/surveillance (supervision, reminders), and activity/stimulation (physical activity, mental stimulation). Jansson et al.'s themes represent the researcher's observations over two half-days in the caregiver's home. This research gets close to what I mean by invisible aspects of caregiving with the categories "empathy/thoughtfulness," and "nearness" as these elements of caregiving are less visible, but they do not address how family caregivers attend to these spaces or the thought process behind them. While this study draws attention to the invisibility of the caregiving role, there are still questions left unanswered by this and other studies about how these invisible aspects of caregiving look. While the outside world sees a list of individual tasks each day, the caregiver may be developing new strategies every day to accomplish each task.

Over a week, a family caregiver provides an average of 26 hours of care to their loved one living with dementia, compared to family members providing other types of care, who give an average of 17 hours a week (CIHI, 2018). The difference is significant, and there are likely many more than 26 hours when we expand the category of "emotional support". There are many hours of emotional support involved in caregiving. A caregiver in the CIHI study states, "these hours can be difficult to quantify" (CIHI, 2018). The care provided extends far beyond the "hours" documented. These hours exist in the spaces in-between visible caregiving tasks. Jansson et al. (2001) state that "[f]amily caregivers' responsibility is much more complex and extensive than is indicated by the visible tasks they perform" (Jannson et al., 2001, p. 811). Invisible spaces of caregiving include how caregivers are using creative thinking within the care dyad.

Creativity is most often associated with the artistic process, but it is also the ability to imagine something different and bring that idea into existence. One way of distinguishing between different types of creativity is by looking at whether or not they refer to an art context. Richards (2010) defines creativity as having two components. Creativity involves the creation of something meaningful and novel (p. 189). Richards illustrates that,

> The construct of everyday creativity is defined in terms of human originality at work and leisure across the diverse activities of everyday life. It is seen as central to human survival, and, to some extent, it is (and must be) found in everyone. Because everyday creativity is not just about *what* one does, but also *how*, creative process as well as product are observed (p. 190).

This definition holds that creativity is something found in everyday life. One does not have to make art in order to be a creative person. The creativity in people's everyday lives can inspire or even *be* artistic products. These artistic products within the everyday required an expanded understanding of how creativity operates.

Richards states,

> Throughout our day, whether at home or at work, we humans adapt and innovate, improvise flexibly, at times acting from our "gut feelings," at times from options we imagine and systematically try out, one after the other. Our creativity may involve anything from making breakfast to solving a major conflict with one's boss (p. 190).

This definition helps one to understand how caregiving elicits creativity. Creativity is linked strongly to well-being. Richards (2007) states,

> [O]ur everyday creativity is not only good for us but also one of the most powerful capacities we have, bringing us alive in each moment, affecting our health and well-being, offering richness and alternatives in what we do, and helping us move further in our creative and personal development (p. 25).

On a very simplistic level, creativity is the act of creating something new. The literature does not show us the strength and beauty in caregiving creativity. There are examples provided to demonstrate how caregivers manage between changing symptoms, routines, and relationships but without showing the extent of their creativity. Creativity is least visible when it comes to emotional navigation.

The invisible aspects of caregiving involve creative thought processes guided by emotion and relationship. Emotion and relationship are what make caring for a loved one living with dementia different from other types of caregiving. Family caregivers do so for more extended periods, and are twice as likely to experience higher levels of distress than other caregivers (CIHI, 2018). An estimated 261,000 of Canadian seniors with dementia are residing in the community (CIHI, 2018) and family caregivers are providing the majority of the care received by people living with dementia (Brodaty & Donkin, 2009). The role of family members is crucial, as there is a significant demand for them to provide care (Iecovich, 2014). Research suggests that without the support of a family caregiver, individuals move quickly into supported living (Brodaty & Donkin, 2009).

Across the world, societies place significant emphasis on remaining in one's own home, as one is ageing with the majority of older adults preferring to "age-in-place" (Iecovich, 2014). More research is needed on what ageing in place means for individuals with dementia and their caregivers (Wiles, Leibing, Guberman, Reeve, & Allen, 2012). As Iecovich (2014) explains, the location where an individual provides care significantly shapes their experience:

> The term place has several dimensions that are interrelated: a physical dimension that can be seen and touched like home or neighbourhood, a social dimension involving relationships with people and the ways in which individuals remain connected to others, an emotional and psychological dimension, which has to do with a sense of belonging and attachment, and a cultural dimension, which has to do with older people's values, beliefs, ethnicity, and symbolic meanings. Thus, the home-space is not just a physical setting of residence but it enables the older person to preserve life history meanings through which a social identity can be preserved even when the older person becomes chronically ill or disabled (p.22).

The present study also considers the unique spaces (or dimension) in the caregiving context. The connection between people and place largely influences the caregiving context as there can be many changes imposed by dementia (for example, transitioning a loved one to long term care). This is another aspect of invisible spaces of care as the context for providing care may change physical locations, which requires even more navigation for the caregiver.

Human geographers have also studied the interactions between caregiving and place from the perspective of "geographies of caregiving" (Wiles, 2003). The metaphor of “landscapes” in relation to caregiving honours the unique spaces of a family member’s caregiving journey. The physical context of care intersects with the emotional context. “Care landscapes” is a term used to describe the “complex social, embodied and organization spatiality that emerge from and through relationships of care” (Milligan & Wiles, 2010, p. 736). This perspective is valuable as it acknowledges that the variables in family caregiving contexts are complex and ever-changing. By conceptualizing care trajectories as “landscapes”, one can acknowledge that care relationships involve people and place (Milligan & Wiles, 2010). Understanding the emotional involvement in family caregivers requires a different definition of space. Milligan and Wiles call for researchers to “disrupt notions of proximity as straightforward geographical closeness, maintaining that even at a physical distance care can be socially and emotionally proximate” (p. 736). In the context of dementia, this perspective is especially relevant. A family caregiver may provide care in a variety of proximities while maintaining an intense caring relationship with their loved one. There is at least one emotional aspect of caring for a loved one with dementia that is unique to the context, and that is latent grief (Dempsey & Baago, 1998). The defining element of the caregiving role is how the caregiver experiences the emotional aspects of their landscape (Milligan & Wiles, 2010). These authors state, “landscapes of care are multilayered in that they are shaped by issues of responsibility, ethics and morals, social, emotional, symbolic, physical and material aspects of care” (p. 740). Physical space and emotion both influence the caregiving role. Family caregiving is emotion-laden because it can be intense and all-consuming. The caregiver’s social and family health context is impacted and informed by the progression of dementia as experienced by their loved one.

Research findings state that family caregivers are a crucial resource for individuals living with dementia (Livingston et al., 2017). Persons living with dementia rely heavily on caregivers, which can bring about intense amounts of pressure, and the role can have a significant effect on the family caregiver's physical and mental health (Livingston et al., 2017; Thompson et al., 2007). Research shows that 40% of family members providing care to a loved one living with dementia experience depression and anxiety (Livingston et al., 2017). The research on stress and anxiety does not mean that caregivers do not experience positive aspects within their caregiving role. There is research to support that both are possible. If we can better understand the caregiving role, then we can design better support. With stronger supports for the caregiver, the likelihood of more positive experiences is higher.

2.5 Impact of Invisible Care

Emotional labour impacts the visibility of caregiving experiences. Evidence shows when it comes to time commitment, developmental and physical stress, and social stress, individuals experience emotional burden while caring for a loved one with dementia (Akpinar, Küçükgüçlü, & Yener, 2011). Emotional labour, a concept developed by Hochschild (1983) in the 1980s theorizes that people attempt to manage their emotions based on individual ideals of how they should or should not feel (Hochschild, 1979). Hochschild (1979) suggested that individuals will try to either evoke a feeling that is not present or, suppress a feeling that is present and unwanted. In the context of dementia, emotional labour can be invisible and assumed to be part of their familial relationship. The problem occurs when, without understanding the emotional depth of caregiving, appropriate support does not exist (Henderson, 2001). Hochschild (1979) writes "…when an individual changes an ideological stance, he or she drops old rules and assumes new ones for reacting to situations cognitively and emotively" (p. 567). If we consider a strengths-based framework for the family caregiving role, there is potential to change the expectations and ideals that a caregiver uses to manage their own and their family member's emotions. The concept of emotional labour draws attention to yet another invisible aspect of caring for a loved one with dementia and draws attention to the need to look beyond the daily care activities and even the emotion involved and look at how caregivers understand their role and their relationship as the care context changes.

The familial caregiving role rarely involves education or training unless individuals seek it out (Chiao, Wu, & Hsiao, 2015). The caregiver and the person living with dementia face many transitions throughout their journey, but the majority of outreach supports and interventions aim to support the person living with dementia. A lack of supportive guidance extended to caregivers means they are navigating much of their caregiving role alone and invisible to those outside the home. As a person living with dementia's symptoms change, the caregiver's role changes as well. In the beginning, providing care to a family member with dementia requires adjusting to a new role, making decisions, and coming to terms with the context of dementia (Adams, 2006). As the disease progresses, the care-recipient becomes more and more dependent on the caregiver.

In some cases, caregivers may feel it is a part of their obligation within the relationship commitment. Adams (2006) suggests a person becomes a caregiver when they take on any level of responsibility for the daily needs of another person. However, the meaning of each caregiver's role in the context of dementia is unique. The caregiving context is primarily characterized by their relationship to the care-receiver (for example a spouse, child, or sibling), the location in which they are providing that care (for example their own home, shared home, assisted-care home), and the hours spent caring for the individual (World Health Org., 2009). The symptoms of dementia involve change and progressive limitation in communication and self-expression. The caregiver can find it challenging to continue to adapt to the changes imposed by dementia. Despite the challenges, the caregiver maintains emotional connection in their loved one's life (Adams, 2006; Erlingsson, Magnusson, & Hanson, 2012; Johannessen, Bruvik & Hauge, 2015).

Individuals living with dementia require a level of care that sometimes exceeds caregivers' expectations. Multiple studies convey that caring for a loved one with dementia results in burnout (Pinquart & Sorenson, 2007) and the need for respite (Watts & Teitelman, 2005; Zarit, Bangerter, Liu, & Rovine, 2017) more than other types of caregiving. However, other studies have found that caregivers find positive aspects in their role (Cohen, 2002; Hughes, 2015) and demonstrate resilience in the face of demands (Donelan et al., 2002; Joling et al., 2016; Windle & Bennett, 2012). Multiple studies discuss that coping is more than getting through a difficult time. Coping is also comprised of incredible strength (Alpert & Womble, 2015; Cohen, 2002; Hughes, 2015).

One author states, “[u]nderstanding dementia as a social phenomenon and a moral responsibility also repositions the family caregiver. Understanding care as a way of interacting and as a way of being in relationship broadens the scope of what it means to care well beyond coping” (McIntyre, 2003, pp. 479-480). Family members have a unique knowledge of the person they are caring for because of their preexisting relationship. This relationship intersecting with the caregiving role means unique navigational skills for the family member. Their ability to attend to their loved one and their specific needs as an individual is significant.

2.6 Making Care Visible

One care philosophy/approach that highlights the components of care that reach beyond the daily activities of living, that makes care visible, is person-centred care. A person-centred approach to caring for an individual with dementia is “an approach to care that respects and supports each individual’s personhood, and that facilitates its transformation and development throughout the disease” (O’Connor et al., 2007, p. 122). There are other approaches to professional and family caregiving for a person with dementia (for example palliative and supportive care) however the principles outlined in Kitwood’s adaptation of person-centred care address the emotional needs of individuals living with dementia specifically. The main distinction between these approaches is that palliative and supportive care are “pathways,” while person-centred care is a “framework” (Hughes, 2015). Over time, approaches to caring for a person with dementia changed from a goal of symptom and disease management to providing care that acknowledges and upholds the person’s individuality (Fazio, Pace, Flinner, &

Kallmyer, 2018; Kogan, Wilbur & Mosqueda, 2016). This occurred through the application of personhood to caregiving approaches. Caring for an individual living with dementia, if it is to attend to the personhood of the individual, shifts depending on the emotional needs on any given day. As the caregivers' path is unpredictable, a framework provides more direction as it can frame any context a caregiver comes upon.

Kitwood's work is an adaptation based on the work of Rogers. In 1961, Rogers published *On becoming a person: A therapist's view of psychotherapy*. Rogers was uncomfortable with clinical terms that objectified individuals as their illness (Rogers, 1961). He discussed the struggle he found with reaching multidisciplinary audiences and even professionals within the field of psychology. He chose to publish *On Becoming a Person…* in book form rather than in a journal because he believed the format would reach broader audiences and specifically, the audiences who needed it most. Rogers believed that person-centred care encourages everyone involved in a similar direction. The direction is "…positive, constructive, moving toward self-actualization, growing toward maturity, growing toward socialization" (p. 27). Rogers states that there are "…strongly positive directional tendencies which exist…in all of us, at the deepest levels" (Rogers, 1961, p. 27). He goes on to talk about the core components for "becoming a person" in psychotherapy. Rogers' discussion of personhood provides a starting place to think about how this study encourages thinking about family members and their loved ones not as a caregiver and a person with dementia, but as two people moving forward, striving for well-being and attending to a familial relationship. Kitwood

(1997) built on Rogers' work by framing these core components as person-centred care in the context of caring for a loved one living with dementia.

Kitwood initiated a significant shift in thinking about the person living with dementia, a new approach in providing professional care, and presented the concept of "personhood" as the single most contributing factor to quality of life. This was a significant change from the biomedical model, which considered dementia treatment only in terms of the disease. As previously noted, Kitwood maintains that every person has five core needs: comfort, inclusion, identity, occupation, and attachment, suggesting that for individuals with dementia meeting these needs requires the unique dedication of their caregivers, as they cannot attend to them on their own.

Kitwood's work has informed scholars for the past two decades and has served as a foundation for today's representation of person-centred care. He suggests that the most crucial role for professionals providing care is to acknowledge the uniqueness of each individual (Kitwood, 1997). He states that through person-centred care,

> …we can be certain that many people will be more at ease with their limitations, more able to live without a historical sense of time or a geographical sense of place. They will feel far better supported, far less alone, in whatever suffering is unavoidable. They will have a new chapter in life, with its own special delights and pleasures (p. 21).

Person-centered care can actually counteract or diminish dementia symptoms by attending to a person's emotional needs (O'Connor et al., 2007). O'Connor et al. state "[a]ttention to personhood has been hailed as perhaps one of the most significant advances in understanding dementia in the past decade" (p. 122). Person-centered care is best practice as it upholds and strengthens the preferences, personality, and potential of the person living with dementia (Kitwood, 1997). He states,

> To do full conceptual justice to the uniqueness of persons in any context is an extremely complex matter. We need to take account of temperament, innate ability, interests, tastes, beliefs, values, commitments, lifestyle, biography, gender, class and culture at the very least. To incorporate even a small part of this into a social science framework requires the eclectic use of several bodies of theory, crossing the conventional boundaries between psychology and sociology. Some of the variability is captured in the concept of personality; the key point is that just as each personality is unique, so also is the nature and color of experience (p. 14).

Alongside the advances in understanding dementia, a person-centred approach to care has also brought significant depth to understanding emotion in caregiving contexts. In the context of providing care to a person with dementia, the centrality of emotion links person-centred care and the family care role. The family caregiver has a pre-existing yet constantly changing relationship in the mix. Dementia can provide challenging moments for the caregiver. In contrast to professional caregivers, the family caregiver is sometimes attending to the needs of their loved one to the detriment of their health and wellbeing. Family caregivers are not able to leave their role at the end of the day. Even if they are physically able to leave (if residing elsewhere), emotional involvement does not finish at the end of a visit. This is different from other caregiving contexts because of the impact dementia has on cognition and communication. Caregivers are constantly adapting to new and fluctuating cognitive dementia symptoms. This means that caregivers are not only navigating their care role but also how to communicate with the person they love. O’Connor et al. (2007) write about understanding personhood as located in the middle of the subjective experience, an interactional environment, and a socio-cultural context.

Family caregivers have expert experience of each of these elements, and while an individual with dementia would have an even more in-depth knowledge, the capacity to communicate becomes more challenging as dementia progresses.

Family caregivers may have the closest insight into what their loved one is going through because they have worked to establish new communication strategies and new connections. The experiences of family caregivers can demonstrate a depth of person-centred care that can inform approaches to professional care and can inform how to better support persons with dementia and their families. At the onset of care, another person becomes a part of the journey, and a caregiving narrative begins. I use the term narrative in this context, referring to the meaning-making process and the resulting story. The act of caring "for" and "about" a family member living with dementia, navigating the caregiving landscape, the attention to personhood, the emotional labour and the meanings that come out of these processes all shape the caregiving narrative.

The expression is as valuable as the meaning taken from the expression. I highlight below, some of the studies that employ the arts in order to open the reader to different types of expression. Swinnen, A., & Schweda state, "[c]reative arts interventions are called upon as a special type of person-centred care and have emerged as systematic and well-described approaches to care" (2015, p.12). I include caregiver narrative studies that use a transformative and exploratory approach as they help to situate the present study. In this chapter, I provided an overview of the caregiving role, as described in the literature. The studies that have provided the most intimate knowledge of what it means to provide care for a loved one with dementia are those that ask caregivers themselves. I would argue that caregivers themselves are not aware of the depth of the care they provide. To understand the extent of invisibility within the role, studies must provide a method of expression that allows participants to explore their narrative and time to process what they find.

In the past two decades, there has been significant growth in research on family caregiving narratives. Narrative approaches focus on the whole story instead of analyzing it in pieces (Frank, 1995). Narrative-based research values the content and method of the participant's story. Palmer (2013) engages with a narrative-based approach and asserts that family caregivers are indeed providing care that is person-centred (in an informal care context and as defined by Kitwood). The researcher explains that they did not hear this information in the interview setting, but in the stories, participants told afterwards about their everyday lives (Palmer, 2013). This gives weight to the argument that participants share a richer version of their narratives when given flexibility in how and when they share it.

Several studies have engaged with caregiving narratives through autoethnography (See, for example, Crisp, 1995; Fox, 2010; McIntyre, 2003; Salmon, 2006). Auto-ethnography is an exploratory approach that incorporates the researcher's personal experience and investigates implications for the broader community (Ellis, Adams & Bochner, 2011). McIntyre (2003)'s work is particularly relevant as it examines the role of personhood in care provided in the community to her mother. She discussed the narratives of paid and unpaid non-family caregivers for her mother (with no prior relationship) and found that dignity is the "the resonant quality, essential value, and guiding principle in an ethic of dementia care" (p. 475). Crisp (1995) employed auto-ethnography to engage with her caregiving narrative and to validate the process of exchanging stories with someone living with Alzheimer's disease. Fox (2010) explores similar themes and frames the narrative exchange with her father using the metaphor of a "mosaic" to simultaneously honour her experience and share valuable knowledge for other caregivers. Another example is Salmon's (2006) auto-ethnography "The Waiting Place: A Caregiver's Narrative". In this article, Salmon uses poetry and diary entries to share her knowledge based on caring for her mother. Her work illuminates "an experience shrouded in silent expectations" (p. 181). Salmon's work creates an intersection between auto-ethnography and creative writing to discuss her well-being as well as her transformative discoveries as a caregiver. She states, "[r]eflecting on caregiving allowed me to attach meaning to that challenging time. I regained a sense of closeness to my mother, reclaimed my history, developed more intimate relationships with my sisters, and now honour caregivers in my clinical practice" (p. 185). While auto-ethnography is a more conventional qualitative method, it opens the door for new understanding of caregiving through deeply personal accounts.

Some studies take the opportunity for creative and personal expression in caregiving research even further. In their study, "Breaking the Fourth Wall…" Quinlan and Duggleby (2009) use participatory theatre to gather caregivers' experiences of hope. Participatory theatre is "grounded in immediate experience and direct experiment" (Quinlan & Duggleby, 2009, p. 207). They state, "[t]heatre is a unique and powerful way of accessing knowledge because it draws out responses that are spontaneous, intuitive, tacit, experiential, effective, rather than simply cognitive" (p. 208). These researchers found that by using theatre to study hope, participants reported feelings of increased hope themselves. The use of theatre with caregivers allows for multiple social and related learning opportunities.

The narrative contributions that tie most closely to the present study is the work of Cole and McIntyre. Over a ten-year period, Cole and McIntyre curated four large-scale multimedia installations which "focused on understanding and representing the emotional complexities of what it means to care for a loved one with Alzheimer's disease" (Cole & Knowles, 2008, p. 401). However, their caregiving research began with sharing their own stories of caring for their mothers. Cole and McIntyre's project titled "In Illness and in Health: Daughters Storying Mothers' Lives" illustrated through a multimedia installation, the reciprocal learning between a daughter and mother within the context of dementia.

> [T]he installations are informed by our independent and collective remembering, reflection, and sense making of our experiences of our mothers in wellness and illness. Personal writing, journals, caregiving notes, photographs, personal documents, and a series of structured conversations helped us to identify points of connection and common themes in our experience. These, combined with the actual creation of the installations, helped us to explore the questions… (presentation, 1999).

Their subsequent installations: "Living and Dying with Dignity: The Alzheimer's Project", "Putting Care on the Map: Portraits of Care and Caregiving across Canada", "Gray Matters: A Collective Remembering of Care" and a performance piece: "Love Stories about Caregiving and Alzheimer's Disease" (Cole & McIntyre, 2008) engaged caregivers in sharing their narratives through artifacts, emblems, photos, and voice recordings. The multiplicity of their methods is an expansion of typical arts-informed methods that traditionally (although a new field) engages with only one or two methods. The multiplicity of methods makes space for multiple layers of understanding the participant's experience. The participant can choose the format of the contribution, which adds unique learning spaces for anyone engaging with the research narrative and perhaps for the caregivers themselves.

In "Putting Care on the Map…" Cole and McIntyre (2008) wove four projects together to explore and elevate understanding of caregiving spaces. Caregivers shared portraits, audio stories and objects of significance to their narrative. The projects expanded the definition of what it means to care for a loved one living with dementia and at the same time, encouraged understanding dementia differently. In "Love Stories…" Cole and McIntyre (2008) produced a script and spoken-word performance based on first-hand accounts from family caregivers. They were able to reach a broader and more diverse audience through staging caregiving narratives. Their work acknowledges the value of diverse formats as a tool for caregiving stories to reach new audiences. Cole and McIntyre (2010) explore and define the act of "paying tribute" in caregiving research. They illustrate "[w]hen called to the caregiving role, so-called ordinary people go to extraordinary lengths to provide creative and imaginative care to their loved ones" (p. 404). They also state that "[a]gainst considerable odds and challenges and often with little systemic support, family caregivers assume and carry out myriad roles and responsibilities in efforts to provide loving care and preserve the dignity of their loved ones" (p. 404). These authors go on to explain that in researching family caregiving we can pay tribute to family caregivers by attending to certain qualities within our work. The qualities of research that “pays tribute” are a vital component of the present study.

Research that pays tribute:

- Invites open and broad participation
- Respects differences
- Appreciates similarities and differences of people’s experiences
- Honours stories as a way of knowing and the process of storytelling as a way of connecting
- Involves deep listening
- Elevates the choice to give care
- Emphasizes the everyday
- Dignifies the ‘domestic.’
- Pays attention to “ordinary” routines of caregiving relationships
- Forefronts relationship in all aspects of the research process
- Respects privacy and intimacy
- Acknowledges diversity and complexity of relationships
- Normalizes challenges of caregiving
- Promotes empathy and understanding across difference

These qualities make a significant contribution to understanding how arts-informed research is a powerful way of not only accessing but lifting the sophisticated and creative work in caring for a loved one with dementia. In care contexts where the care receiver is living with dementia the family caregiver and the person they are caring for, are piecing a puzzle together without the box. They do not know how the end picture is going to look. How much of this story we hear depends on how much space researchers provide. “Paying tribute” involves more than listening. It is a way of holding researchers morally accountable to those sharing their experiences (Cole & McIntyre, 2010). Creative representations of narratives use metaphor and symbol, imagery, and story to illuminate not only caregivers’ daily activities but also the in-between spaces of caring. As Saks

(1996) states, “some things can only be known by feel, innuendo, by implication, [and] by mood” (p. 413).

In this chapter, I provide an overview of how relevant literature frames the family caregiving role. I demonstrate how the activities associated with caregiving are extensive, and due to the emotional commitments a caregiver feels to their family member, the complexity and intensity of care is often invisible. In addition to learning more about the caregiving role, making visible the invisible spaces of caring brings new knowledge to understanding dementia. A caregiver’s knowledge of dementia is the closest insight available, next to the person with the illness. In the next chapter, I provide an overview of my methodology and address how “paying tribute” to caregiving narratives through an arts-informed approach sets the stage for caregivers to share the depth of their context and make their experiences more visible.

Chapter 3
Methodology

Plate 1 My father and my son.

> Bringing together the systematic and rigorous qualities of conventional qualitative methodologies with the artistic, disciplined, and imaginative qualities of the arts acknowledges the power of art forms to reach diverse audiences and the importance of diverse languages for gaining insights into the complexities of the human condition.
>
> (Cole & Knowles, 2008, p. 59)

Creativity and emotion are a central focus in this study, and they are central components in the chosen methodology**.** Creativity is both the tool and the subject, and together they generate meaning. In this study, I explore the caregiving experience through a methodology that creatively facilitates an arts-informed space for family caregivers to explore their narrative and share their knowledge with the community. In this chapter, I provide a rationale for my research methodology through an overview of my landscape as researcher, the methodological landscape, the research design, representation through creative text, audience and feedback, and finally how I attend to the qualities of goodness in arts-informed research.

3.1 Researcher Landscape

I started my doctoral program, thinking that completing a master's thesis was the only experience that qualified me to do this research. Since then, I acknowledged that empathy, patience, and strong listening skills were other vital qualifications that I have. I also am an artist who paints and sings. During my Ph.D. program, both of my grandmothers were diagnosed with dementia, and one passed away. I became a mother and a stepmother. I lost my father traumatically and then my stepmother, and I have battled with mental health challenges. I also have performed, painted, and found mentorship. As I write this, I feel proud of the time I took to write and the tribute I am paying to the family caregivers through this work.

There are many ways of knowing, and one of these is reflecting on what one knows and, at times, realizing that one's perspective of what one knows can shift. I started this life on a farm nestled within a mountain forest and overlooking a deep valley. I spent every day exploring, and there were places I could see but would never know. Expressions of knowledge can take many forms. Sometimes it takes someone else interacting with our expressions to be aware of the depth of our knowledge. I used to walk through the horse field or the woods making up songs. The content was emotion-driven and in response to things which I was too young to understand. Creativity has always been a comfort and support throughout my life. As a teenager, I became familiar with end of life care as I watched my mother care for my much-loved older sister, who lived with cancer for three years and eventually passed away.

Music, art, and sometimes writing were ways of expressing emotions and experience, but to recognize these expressions as valuable knowledge, I sought out validation from others. This became most apparent during my master's thesis research as I sat next to women with advanced dementia and they shared expressions of their knowledge in unconventional ways. They were not able to respond to my questions or tell their story in a linear language form. They were able to communicate through repetition, movement, and in other interactive ways. The family caregivers shared stories, which added verbal context to my interactions with the women. One of my favourite stories is a woman who paced the hallways pointing her finger at the walls and reciting numbers with no seeming order. Her husband told me that these numbers were serial numbers on expensive china. They had worked together for many years in a china shop and accounting for inventory along the wall shelves was an important part of her life's work. I resonated with and valued the women's many forms of expression, and the time it took for them to be able to communicate what they wanted to say.

Over the past 35 years, I have used the arts to grieve and to celebrate and, later, to understand the value in sharing my experiences. My experience of loving two grandmothers living with dementia taught me the value in honouring unique forms of expression. Completing this dissertation has been difficult as my writing is never as clear as when I use other mediums. In the midst of my writing stage, my father had a long battle and eventual loss of life. I attribute his death to his inability to express his own painful experiences or know his strength. A year before he died, however, he built the most beautiful greenhouse and flooded it with cherry tomatoes. He delivered tomatoes to people with whom he had lost connection over the years. My most beautiful memory of my father was seeing him standing at the entrance to the greenhouse with my two-year-old son. My dad pulled down a branch so my son could reach a tomato. I returned home and began sketching that moment. That piece of art let him know the strength I saw in him. It was one of the only things in an empty room on the night he passed. These moments of recognizing strength and creativity allow something beautiful to emerge from overwhelming emotional moments that seem to last a lifetime. I am proud that I took the time to make music and art when I could not write, and I hope this research has offered some of those same spaces to others.

Qualitative research offers opportunities through different methodologies to uncover and share knowledge. All methods of researching present opportunity but also limitation in how knowledge is engaged. Research methodologies are bound and sometimes constricted by assumptions. Methodological choice allows researchers to think about their perspective and the purpose driving their research and to align elements of the work accordingly. As a researcher, I value the participants' unique creative expression and their right to decide what it looks like. My background in gender studies guides me to look for ways to diminish disempowering structures and processes. As a white, middle-class woman who lives in a warm house with a bi-weekly pay cheque, I am aware that I am privileged and make every attempt to place higher value on voices that do not come from a place of privilege. I chose a research path that offers a platform for different types of knowledge expression and I acknowledge that people do not always want to talk about difficult emotions. For this research, I chose an arts-informed methodology to address power imbalances embedded in conventional qualitative research methodologies that are not always flexible in valuing different forms of knowledge and ways of knowing. This methodology, among other things, provides a more balanced relationship between myself and the participant because I was able to give more weight to what the participants needed in terms of time, space, and medium to express their experiences.

3.2 Methodological Landscape

3.2.1 Qualitative Research

This study is well-matched with a qualitative research paradigm, as the objective of both is to draw attention to invisible spaces. At its core, a qualitative paradigm "consists of a set of interpretive, material practices that make the world visible" (Denzin & Lincoln, 2011, p. 3). In the context of dementia, some elements of the act of caring are visible when considering everyday tasks. The creative thinking and the resulting action when everyday tasks present stumbling blocks are where the invisibility lies. These thoughts and actions work with and around meanings derived through interaction between family members that others would not recognize. Through the arts, the research process and resulting exhibit materialize what a person thinks, feels, and decides into an engaging and experiential form. The caregiver's world is made visible to those who are not privy, through the act of representation in arts-informed research. At the center of qualitative research practices are representation, interpretation, and transformation, with a critical element of reflexivity (Denzin & Lincoln, 2011). In qualitative research, there is much discussion of how one constructs knowledge and how people make meaning of their own experiences. Qualitative researchers also reflect on their ways of knowing. The researcher's life experiences and perspectives shape the research, and a qualitative paradigm expects reflection on this. There are multiple ways of learning about people's everyday lives (Eisner, 2008). Eisner compares the multiple avenues of knowing to describing the taste of water to someone. He asks whether this is something that one does through words and, if not, then there are likely other experiences that required more than words to understand. Caregiving is one of those experiences. When I asked caregivers to speak about their experiences, I found there was a lot to tell. In this study, I wanted caregivers to have an opportunity to talk for as long as they wished but then I also wanted to give them space to look deeper, to recognize the extent of their strengths through creativity. In qualitative research, the researcher makes the participants' knowledge a priority in each methodological choice. As a qualitative researcher, I made choices with the hope that participants would feel comfortable, respected, and honoured for their presence and contribution.

In qualitative studies, the researcher acknowledges her role by being both transparent and reflexive (Denzin & Lincoln, 2011). I attended to these aspects of my role as a researcher by personally accounting for how my presence contributed to shaping the study and by reflecting and communicating with participants throughout each stage. A feminist lens informed my decision-making throughout this research. A feminist approach includes questioning knowledge production, ownership, and objectives (Olesen, 2011). I accounted for my presence in the study by conceptualizing within the research design how participants could own their knowledge, experience, and creative expression and make decisions around those things. One of the concepts I put in place was to think of the participant as having multiple facets of their identity. Yes, they were participants in my study, but it was also their study, their story, and their creativity.

Each individual entered the study as a participant and, as she/he shared their story in the initial interview, I came to know them as a caregiver. Then, as they engaged their creativity and the arts to produce an exhibit piece, they became artists within the study. Denzin and Lincoln present the metaphor of a qualitative researcher as "bricoleur" (Denzin & Lincoln, 2011, p. 4). As a "bricoleur" I produce "bricolage" comprised of "…a pieced-together set of representations that are fitted to the specifics of a complex situation" (p. 4). The concept of "bricoleur" complements the design of this study as caregiving stories are complex and there is value in different pieces of expression in that they communicate different things. In most instances, the creative expressions were an expansion on what participants told me during the interviews, but there were also pieces that participants only shared through creative expression.

I engaged participants in an initial interview to establish a rapport and to discuss the boundaries of the study. The initial conversation with participants allowed them to get to know me and then to tell their stories before I asked them to produce a creative piece. I then invited the use of various art forms to encourage the participants' expressions to grow and blossom in whatever ways they felt necessary. As not everyone is familiar or comfortable with expressing themselves creatively through the arts, I chose to transition from a traditional interview and then ease into discussions of creative expression, which would be the starting point for thinking about a creative arts project to share their caregiving experience. Arts-informed methodology was the best way to frame my methodological objectives because "words, except when they are used artistically, are proxies for direct experience" (Eisner, 2008. p. 5). In order to learn about creativity in caregiving, I employed a methodology that values and prioritizes creative expression as knowledge.

3.2.2 Arts-informed Methodology

In the early 1990s, qualitative researchers began looking at creative alternatives to traditional research methodologies. What prompted this shift was discontent concerning how the academy was neglecting to represent human experience (Cole & Knowles, 2008). Cole and Knowles' (2008) experience was that "[i]ndividuals and their lives were flattened into a form mostly unrecognizable to those directly and indirectly involved or represented" (p. 57). Cole and Knowles (2008) explain:

> [W]e sought what we considered to be more appropriately inclusive approaches to inquiry processes and representation methodologies that honored the diverse forms of knowing that were part of everyday experience and that paid appropriate respect to both research participants and those who "read" or might be interested in "reading" research texts (p. 57).

Researchers started to explore incorporating artistic components into research methods to make meaningful connections with audiences outside of the academy (Cole & Knowles, 2008). These efforts made a significant impact by the late 1990s, and scholarly journals were more open to publishing research that represented multiple forms of knowing (Cole & Knowles, 2008). Arts-informed research became a *bona fide* methodology, along with other arts-related methodologies (arts-based research, art-based inquiry, image-based research, and visual sociology), and today the arts have become noticeably more prominent and present in research. Arts-informed methodology highly values the arts as a mode of knowledge expression within an arts-informed methodology. In my work, I see the arts as an opportunity for research to have a function beyond the researcher's questions. That function is for research to show the significance of participants' stories alongside and sometimes beyond words. In this study, the stories are not merely collected but evolving and, through the arts, they create informative and experiential data of which participants are proud.

Arts-informed research is a qualitative research methodology within the social sciences field that is "influenced by but not based in the arts" (Cole & Knowles, 2008). It is a relatively recently developed field that offers a platform to enhance engagement with knowledge through creative means. Arts-informed methodology challenges the positivist paradigm by aligning its methods to match the depth of human experiences, which exist beyond conventional ways of gathering and representing information. The depth of caregiving emotions can significantly vary, as shown in the previous chapter. As a researcher, I could not presume that participants would feel comfortable talking about their feelings. An arts-informed methodology "creates new understandings of process, spirit, purpose, subjectivities, emotion, responsiveness, and the ethical dimensions of inquiry" (Cole & Knowles, 2008, p. 59). It also engages "…the multiple dimensions that constitute and form the human condition – physical, emotional, spiritual, social, cultural – and the myriad ways of engaging in the world – oral, literal, visual, embodied" (Cole &

Knowles, 2008, p. 60). Knowledge representation through arts-informed methods brings new depth of understanding, but also opens minds to different methods of accessing that depth. An arts-informed method of inquiry is a flexible framework on its own and as a complement to other methodologies as well (Cole & Knowles, 2008). There are seven key components (Cole & Knowles, 2008) in arts-informed research: commitment to one or more art forms, integrity in methodology, creativity in inquiry process, researcher presence, researcher reflexivity, audience engagement, and reaching audiences beyond academia.

Researchers that engage the arts provide opportunities to understand their subject matter in various lights. Leavy (2018) highlights that:

> [a]rt, at its best, has the potential to be both immediate and lasting. It's immediate insofar as it can grab hold of our attention, provoke us, or help to transport us. Our response may be visceral, emotional and psychological, before it is intellectual. Art also has the capacity to make long-lasting, deep impressions (p.3).

The benefits of research that engages the arts are benefits to researcher, participant, and community. Leavy (2015) identifies the following attributes to research that engages the arts:

- New insights and learning
- Describe, explore, discover and problem-solve
- Forge micro-macro connections
- Holistic
- Evocative and provocative
- Critical consciousness, raising awareness, and empathy
- Unsettle stereotypes, challenge dominant ideologies and include marginalized voices and perspectives
- Participatory
- Multiple meanings
- Public scholarship and usefulness

Consideration of these components, ideally, leads to a transformative and experiential process for all those involved. In this study, that includes researcher, participant, and audience. The key components also provide a framework for evaluating arts-informed studies. My choice of an arts-informed research methodology stemmed from my previous research and from the literature where I observed that creative expression could play an essential role in the lives of family members providing care to a loved-one living with dementia. I wanted to engage caregivers in a creative process that allowed their experiences and knowledge to come together in a project that others could appreciate as a work of art. The following section illustrates how this process occurred and the considerations made throughout.

The purpose of arts-informed research is to “enhance understanding of the human condition through alternative (to conventional) processes and representational forms” and “to reach multiple audiences by making scholarship more accessible” (Cole & Knowles, 2008, p. 59). I addressed these goals through a commitment to knowledge representation that extends beyond the written text and an academic audience.

3.2.3 Arts-informed Methods

Arts-informed research methods situate participants as active and authentic knowers who strengthen research through their involvement (Eisner, 1993). The participants in this research informed the research at every stage through creative expressions, and they expanded the language around caregiving and dementia so it could include artistic form. From early in the planning phases of this study, I considered the value that the participants brought to this research and how they might benefit from the process alone. As I contemplated research design, I considered methods that would lead participants down a welcoming path so they could explore their experience, share their creativity, and expand the field of knowledge in terms of the caregiving role. Each stage of this research took a sensitive, empathetic, and positive approach with participants and their contributions. I did this by listening and adapting to participants' needs as they arose.

3.3 Research Design

The overall design of this research includes three spaces of knowledge production. The first space is where the participants and I meet, they tell me about their caregiving journey and their creativity. This first space is conceptually an interview, but it is also a chance to communicate my goals to engage them respectfully and honestly. The interview was loosely structured so that the participant could tell their story in a way that was meaningful to them. I wanted the participants to know right away upon meeting me that their voice held value, and they had choice of how they wished to express it within this study. I chose to be absent from the second space so that the participant could reflect and engage with their creativity in their own time and find new expressions for their voice. I thought back to my experiences in other studies where I conducted traditional interviews, and I wanted my participants to have more than a moment to think about their response. My absence in this second space allows the participant time to reflect on what they would like to create. The final space is where I meet the participants at the exhibit, they see their creative projects as art, and together we engage with the community as audience.

The study took place in St. John's, NL, Canada between 2012 and 2014. Memorial University of Newfoundland’s research ethics council approved the study in 2011 (Appendix A). The inclusion criteria required participants to have experience caring for a family member living with dementia. I sought 10-12 family members. I chose this number to allow a flexible timeline for participants. A small group enabled me to develop a rapport with the participants and provide encouragement during their creative process. I displayed recruitment posters around the community and in clinical settings. The Seniors Resource Centre (now known as SeniorsNL) and the Alzheimer’s Society of Newfoundland and Labrador supported this study by promoting it within their caregiver support groups and through their online communications.

As participants entered the study, I met with them for an initial interview. I recorded each interview with a small handheld digital recorder. At the end of each interview, I gave each participant a checklist (the creativity cue–described below) to hear their thoughts on their creativity. After each interview, I transcribed our conversation, read the transcription several times, and made notes. These notes captured dominant themes in their story and the metaphors and imagery in their words. Based on the transcripts and the creativity cue, I also made notes about each participant’s creative interests, their understanding of creativity, and their comfort level with creative expression. I then met a second time with participants and shared my notes with them.

The second meeting was where we discussed what the process of sharing their experience might look like using creative mediums. The next component of their participation was to put together a creative project with the end goal being to share it in an exhibit. While the majority of participants did not ask for help with their creative projects, I met with a couple of individuals upon request to assist with brainstorming, gathering materials or assembling materials. I gave participants the freedom to choose any arts-based form, and they were encouraged to use multiple means of representation. As we discussed metaphor and symbol, we talked about arts-based activities they had interest in and brainstormed ideas for their project. Ideas arose organically through our discussions.

The objectives of the creative projects were to communicate participants' caregiving experiences through the arts, through experiential and familiar materials that felt meaningful. Following the completion of their creative project, we discussed how they would display it in the exhibit, and I asked each participant to produce an artist statement to accompany their work. When all participants completed their creative projects, we brought them together at a public exhibit and invited the community to attend. I invited participants to sit or stand with their projects and to speak at the event. I describe the steps further in the sections below.

3.3.1 Initial meeting with participants

The purpose of the initial meeting was to establish a rapport with the participant and to bring a subject and its history into a present moment. Peräkylä and Ruusuvuori (2011) state that "[b]y using interviews, the researcher can reach areas of reality that would otherwise remain inaccessible such as people’s subjective experiences and attitudes” (p.529). While there is truth to this, through this work, the reader has a chance to see how the depth of knowledge generated in an initial interview can go further through creative intervention. Therefore, the interviews in this research are a starting point and a meeting place where creative methods can follow. The participants chose the location for each interview. I found myself sitting in kitchens and living rooms, a work lounge, and a boardroom. We talked at locations in St. John’s and rural Newfoundland. I prepared an informal and flexible interview guide, not to follow a sequence of questions but to reflect on whether participants covered specific topic areas. These areas or categories (Appendix B) were caregiving and dementia, support, creativity, and arts. For the first category, I asked the participants to tell me about what it means to be a caregiver and their understanding of dementia. I also asked them to discuss their relationship with their loved one, and the transitions they experienced during their caregiving journey. For the second category (support), I asked them to discuss familial and other types of support. I also asked the participants to talk about any hobbies they have. For the third category (creativity), I asked participants to discuss creativity in their caregiving role. I also asked them to define, in their own words, what it meant to be creative. I placed the fourth category (arts) as the final topic to end the interview on a lighter note. For the final questions, I asked participants to discuss when the arts (in any way: participation, attendance, creating) had been a part of their life. Finally, I asked each participant what it means to be an artist and what arts-based activities interested him or her.

The “Creativity Cue” (Appendix C) is a research tool I developed to add another way of gathering information. The tool is a prompt that facilitates a dialogue that includes self-talk and encourages participants to think aloud while evaluating their level of confidence in creative activities. The Creativity Cue is a list of creative arts activities with a few non-art activities (e.g., gardening). I gave the participants the printed list and asked them to go through it with a pencil and talk it through aloud. The list prompted participants to mark whether they do each activity as a hobby or as part of a group, to sell or show, as well as their level of interest/non-interest. While participants marked the list, they spoke about memories and experiences, many of which they had not considered part of their caregiving experience. I was able to gauge not only their arts-informed interests but also their confidence in and understanding of creativity within their caregiving role. This tool and the discussion around it generated a creativity inventory.

The purpose of the inventory was to capture how participants felt about their creativity and their thoughts about creativity in general. The space created by the inventory served as the cue for the creative project. The inventory cued caregivers to begin thinking and speaking about their creativity and, as a result, I was able to determine a sense of how much direction or assistance each participant needed with their project. Another benefit of collecting an inventory was to get a sense of whether the participants were aware of creativity in their everyday life. This inventory, alongside the interview transcript, created a bridge for participants between understanding creativity as more than one’s involvement in the arts. Following this initial discussion of creativity in daily activities of living, we could then transition into discussions of creativity in daily activities of caregiving.

3.3.2 Second Meeting

The purpose of the second meeting was to bring the themes back to caregivers. I transcribed the interviews within 1-2 weeks so I could share them with participants and they could begin their creative project as soon as possible. My initial read-through of the transcripts produced examples of creativity in caregiving. Examples included creative thinking in the context of providing care and, more specifically, strategies to ensure their family member felt loved. I considered examples of creativity also to be examples of strength. The purpose of collecting these examples was to generate themes, imagery, metaphors, and symbols from the participants' own words and to encourage them to consider how their strengths/creativity could inspire a creative project. There is much benefit for caregiving contexts in drawing attention to the strengths that exist, rather than focusing on weaknesses (Peacock et al., 2010). A strengths-based approach does not ignore the challenges or frustrations, but honours the story and experience as a whole. As I brought my findings to each participant, I saw excitement, pride, and surprise all as reactions to their creativity. They had shared their stories without even recognizing the presence of creativity.

3.3.3 Creative Process and Product

The creative project stage of the research sat between the interview/inventory and the exhibit. The creative projects could be any form of artistic expression, and, in some cases, participants chose multiple mediums. As Higgs (2008) states, "[a]rts, as creative acts, provide a perfect opportunity to create a new metaphorical model to illustrate the subject or question under study" (p. 552). Each participant's inventory of engagement and confidence in the arts was unique; therefore, my level of involvement and guidance for each project varied. I encouraged participants to engage with mediums that allowed them to express their stories and, in multiple cases that meant using multiple mediums.

Participants worked with mediums that sparked interest for them. My discussions with participants about their potential projects stemmed from the Creativity Cue and from the metaphors they used in telling their story. Participants engaged with multiple mediums including painting, sketching, comic-strip, play-dough, song-writing, mixed media, felted-wool, film, photography, singing, short-story, poetry, embodied/performance, and metaphorical representations of creative caregiving. The meaning inscribed in these projects blends the caregiver's story, the process of using the arts to represent meanings from the caregiving process, and their reflections on their relationship with their family member.

3.3.4 Exhibit

I employed the arts as a method of reflecting and creating stories, but also as a way of sharing those stories with the community. In Lapum, Church, Yau, Mathews David and Ruttonsha's (2014) discussion, an exhibit or installation is characterized as an "experience" where one presents the community with primary data or the original story alongside the researcher's interpretation. These authors explain that the benefit of the art exhibit as a way of disseminating research findings is that it allows people to develop a connection to the experiences shared. In this research, each participant wrote an "artist's statement" which included their knowledge and experience in caregiving, what their creative project was meant to communicate, the materials, the process, and their feelings. Each participant titled their creative project and both the statement and a card displaying the title accompanied each project. In this study, participants were in control of what written context they wanted to accompany their original product.

Before the exhibit, I considered myself a curator of a valuable collection. My role was to assemble, manage, and present the collection of artistic projects with attention to each component of each artist's work. I spent significant time considering the venue and the exhibit space. The large amount of light through the generously sized windows was the deciding factor. In Cole and McIntyre (2007)'s "Context Matters", this attention to the space can "bring opportunities for connection between viewer and text" (p. 312). The exhibit was an opportunity to showcase the participant's creativity, provide a point of connection among participants and between audience and the caregivers' experiences.

3.4 Representation through Creative Text

An "open" text presents a set of themes and stories that welcome those who engage with them to attach their significance to what is experienced (McIntyre & Cole, 2007). In this study, the themes that emerged in the creative projects represented everyday life and emotion in the caregiving context. The projects were accessible because they were broadly relatable. Even if a person could not relate to an expressed emotion, s/he could relate to the everyday. The experience is similar to people having different interpretations of a song. A song can mean very different things to different people even though an artist writes with a singular meaning. I attended to the accessibility of the text by thinking about both the creative projects and the exhibit as a cohesive unit. I considered a range of venues but chose one that provided a warm and welcoming space to engage and a separate space for time alone. I considered what was visible through the windows, what covered the walls, and the physical space for the caregivers to be with their projects. The room, the participants, the projects, and the audience were all a part of the “text”.

3.5 Audience and Feedback

Engagement with the audience is a significant component of this study. Sharing the research throughout the process allowed an opportunity for reflexivity. In holding an exhibit, participants and researcher were able to hold a mirror to their work. Eliciting feedback meant needing to be comfortable with the vulnerability involved in not knowing how others will respond to creative expression. It is a way of making research accountable and authentic. Documenting the response to my research allowed for a research process that was transparent and collaborative. My presence and the participants’ and the audience/attendees’ presence were held up to the light. Following the exhibit, I also asked for feedback from the photographer and the caregivers. After I provided the participants with the audience feedback, I asked for their reflections about their experience participating in the research. I included places for audience members to write comments in hopes of creating a space for attendees to express appreciation and empathy. The feedback was one way of evaluating the research. The participant and audience responses to the exhibit allowed me to evaluate the merit of my methods and the choices therein. The consideration of feedback from those involved in the study is one of the ways I attended to its “qualities of goodness” as outlined in the next section.

3.6 Qualities of Goodness in Arts-Informed Research

Evaluating arts-informed research requires a careful analysis of how it adheres to “qualities of goodness” (Cole & Knowles, 2008). Just as conventional qualitative research is evaluated through standards of rigour such as transparency, reflexivity, et cetera, arts-informed research also has standards. Cole and Knowles (2008) established a set of standards, which they term “qualities of goodness”. These qualities tie together the components of well-designed research. The “qualities of goodness” are: intentionality, researcher presence, aesthetic quality, methodological commitment, holistic quality, communicability, knowledge advancement, and contributions. Arts informed methodology allowed this study to attend to each quality and the associated attributes as outlined below.

Intentionality

The broad intention of this study was to deepen our understanding of how family members navigate the care role and how creativity is a part of this. Further to this, I wanted to make a space for caregivers to communicate their experiences and emotions through expressive methods that honour their knowledge as valuable contributions to society and research. In sharing their knowledge through the arts there is a strong element of connectivity with the audience and other caregivers and, consequently, an opportunity for transformation. I hoped through the creative projects and the exhibit, that caregivers would communicate not only their story but also discover their strengths. Through facilitating a possible site of transformation, I hoped that the individuals involved would engage with their caregiving story in ways that inspired them and others. I hoped that, at some point during the process, they would see how their story contributes to a shift in thinking about caregiving and creativity. I hoped that they would see other caregiving projects and feel a sense of community and compassion. Overall, I hoped that those who were at the exhibit and those who can only engage with this thesis would experience something similar. This study encouraged transformation in participants, the audience, readers, and myself, but also in how we approach understanding the experience of family caregivers in the context of dementia. I was able to illuminate caregivers' creativity in spaces that research does not typically access. This study is pairing creativity as a theme across content and method to advance what we know about caregivers but also how we come to know.

Researcher presence

Throughout the study, I have been transparent about my presence through being reflexive at each stage of the process. I communicated (with participants) my thoughts and feelings towards the research topic as well as my personal and professional experiences. I shared this information with all those involved, from the ethics proposal to this final writing stage. I spent a significant amount of time thinking about the decisions I made throughout the process and how they shaped the exhibit and this thesis. I positioned myself as curator but also spent time in the artist role as I assisted with some of the creative projects. Explicitly showing how the researcher is present within arts-informed research is essential to ensure transparency and clarity in the research texts (Cole &

Knowles, 2008).

Aesthetic quality

One does not evaluate arts-based works for their aesthetic beauty or artistic quality but for how they communicate and honour the artist's story. "The quality of the artistic elements of an arts-informed research project is defined by how well the artistic process and form serve research goals" (p. 66). In this study, I employed the arts to engage with the depth of emotion and, consequently, the creativity involved in navigating the complex situations dementia imposes. I showed each participant respect by acknowledging that caregiving is an art form. I referred to each caregiver as an artist by giving adequate space for how they chose to represent their knowledge. The considerations I made as researcher gave each participant's piece a space to be honoured, engaged with, and considered a piece of art. Asking each participant to display an artist statement conveyed this respect.

Methodological commitment

A methodological commitment in arts-informed research means a "principled process, procedural harmony, and attention to aesthetic quality" (2008, p. 66). One of the key concepts I kept returning to throughout the research process was considering how I attended to the research in a way that others will recognize as harmonious, despite the flexibility and at times fragmented parts. It was important that despite the open and creative formats, timelines, and levels of researcher involvement, that the pieces would come together with coherence. I gathered the pieces in at least two ways. First, I ensured that discussions of creativity and strength guided the work. This meant that the projects would fit under a single theme with variations of presentation and content. Second, in knowing we were all coming together in a single time and space, I spent much time thinking about how to attend to the space within the exhibit, so there were threads throughout the room. I asked all participants to create a title and write an artist statement. All projects had a similar table with white cloth to present their piece. All tables held a notebook for feedback.

Holistic quality

In arts-informed research, the evaluation of holistic qualities involves considering how authentic, coherent, and consistent the research is (Cole & Knowles, 2008). Throughout this research, I responded to participants' feedback by making changes to accommodate their comfort levels with materials, space, and time to create. I valued the needs of the participant above my objectives. I carefully considered representation within the exhibit and how to display the depth of emotion communicated through the creative projects. I was careful not to take segments of caregivers' narratives but instead presented their expressions as knowledge and text in their immediate form.

Communicability

This study had a significant level of communicability, as I considered multiple research texts and ways of knowing. The process of putting together a creative project allowed the participants to think about their knowledge and experience from a creative and strengths-based lens. I discussed the process with each participant and allowed for diversity so participants could find their meaningful way in the project. The exhibit venue meant a space where caregivers could access other caregiving experiences, but also come to know their own experience through others' eyes. The exhibit provided an opportunity to experience the transformative nature of arts-informed representations that elicited empathy, understanding, and respect.

Knowledge advancement and contributions

When I planned the research, I considered what the participants hoped to gain from the process and how much or little they wanted direction. Each participant entered the study at a different time, and thus began the creative process at a different time. The stages flowed forward and backward and, because of this, I engaged with one participant at a time and was able to attend to anything they might need for their piece to develop.

Evaluating arts-informed research involves considering how it is evocative, accessible, and transformative, as well as its ability to reach diverse audiences (Cole & Knowles, 2008). These elements were the key objectives I wished to accomplish in using arts-informed research. In engaging with both written and creative arts texts, I envisioned a study that would be accessible to community and academic audiences. The capacity of the caregiving stories to evoke understanding and empathy was never something I questioned. The arts, however, made these stories transform a research space into a community art exhibit where family members transformed into artists and their caregiving stories into pieces of art. The feedback from the audience relayed that the exhibit achieved communicability. In arts-informed research, one presents knowledge, but as I referenced earlier, it is not intended to stop at a singular meaning. The audience involvement and the potential of self-discovery for participants through the creative process encouraged multiple and evolving interpretations. In the next chapter, the reader will come to know the participants as caregivers of family members living with dementia and as individuals tending to the needs of a family member.

Chapter 4
Caregivers

> Interpretation is thus inherent in storytelling; both tellers and listeners constantly interpret each other. In a functional sense, storytelling prepares people for encountering difficult situations, but often the story itself is the difficult situation. Interpretation is necessary for deciding how to respond to a story: whether to pay attention at all; if attention is paid, how to react (laughter or tears, indignation or affirmation); and if the story is told in conversation, what story to tell next.
>
> (Arthur Frank, 2010, p. 86-87)

Making a visible space for stories is a theme woven throughout this research. The way we understand dementia and care for the person living with dementia relies on stories and as this study demonstrates, there is value in expressing caregiving stories in multiple ways. Frank (2010) highlights, “often the story itself is the difficult situation” (p. 86), meaning that some stories need room for reflection and growth. Caregiving for somebody with dementia demands that a person think creatively about her/his changing care context. Each caregiving story has its unique twists and turns. Creativity allows a caregiver to adapt to changes in their loved one and the relationship. Sometimes, creativity is what happens naturally when a person needs a solution to an immediate problem. One can also invoke creativity through planning. In this chapter, I attempt to present the full spectrum of creativity in the everyday lives of caregivers while also demonstrating through the creativity cue that all individuals are creative and that this creativity exists in and beyond the arts. This chapter illustrates how I began to blur the boundary between creativity and art for the participants so that they could think about their creativity as something that they already possess, that holds value, and that can be beneficial in their lives and others. Through creativity, the role of a caregiver and their relationship with their family member is nourished. In this chapter, I introduce the reader to each caregiver and their unique strengths in creativity and caregiving. As mentioned earlier, to illuminate invisible care spaces, I use Kitwood's five essential needs for an individual to experience love.

Need	Description (Kitwood, 1997)
Comfort	This word, in its original sense, carries a rich array of meanings: tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety.
Attachment	Without the reassurance that attachments provide, it is difficult for any person, of whatever age, to function well
Inclusion	Becoming part of the action and having both a place and a role
Occupation	To be occupied means to be involved in the process of life in a way that is personally significant, whether this consists of action, reflection or relaxation.
Identity	To have an identity is to know who one is; it involves maintaining a sense of continuity with the past, and some kind of consistency across the course of present life. Identity involves having a 'narrative'—a story to tell about oneself and one's life.

The following section highlights how the caregivers in this study navigate their care spaces and how they use creative thinking to ensure their family member feels comforted, attached, included, and occupied, and maintains a sense of self. I chose these five needs because they draw attention to what it is that makes caring for a loved one with dementia unique, but also because they lend a name to the emotional navigation required in the family caregiving context. Each caregiver in this project tells a story from their perspective of life as a caregiver. Some caregivers tell a story about the day before, and others tell a story that spans many years or even a lifetime. All of their stories are about strength and creativity. I have divided each introduction into three parts for each individual: the interview, the creativity inventory, and the creative project. Throughout these sections, I include quotations from the caregivers. While I cannot provide the entirety of the transcripts, I can give the reader a glimpse of what participants shared.

I arrived at each initial meeting prepared for an interview to occur, although these meetings did not feel like interviews. There was formality involved because of the consent form (Appendix D) and the voice-recorder, but it was also a space for informality. I had my set of questions in the interview guide so there would be consistency across the participants, but I found myself paying careful attention to each person I met. I wanted to establish a connection based on how privileged I felt to be sitting and hearing their story and how in most cases, they were sharing their home-space with me. Each meeting had an exchange of gratitude for a space to tell and a space to hear the story. The caregivers spoke with me in their kitchen, living room, and workplace and in one case, on the phone. They made me tea and offered me baking.

The interviews began with a general question about their caregiving story. I tried to let each caregiver steer the conversation so I could hear what was important to them to share. When they finished, I wrapped each interview up with a conversation around their creativity. I presented each participant with a Creativity Cue. The Cue provided twenty-three activities down the left-hand side (e.g. writing, singing, carpentry…) and six columns across the top that asked for the participant's level of interest (hobby, interest, sell/show, group, "I am not good at it", and no interest). The purpose of the list was to prompt the participant to talk about their experience with each item but also to get a sense of their awareness and confidence in regards to their creativity. I used the inventory as a tool to encourage a broader conversation about creative activities but also as a tool for gathering insight into how the participants used creativity in their daily lives. The participants' dialogue about their creativity conveyed more than what they marked down on paper. Following the interview and inventory, I completed an initial read-through of participant transcripts. This initial analysis involved combing the transcripts for examples of creativity in their caregiving role. The goal of this initial read-through was to highlight caregivers' creative strengths and bring that back to them in a second meeting. I asked caregivers to think about their creative strengths by drawing their attention to themes, symbols, and metaphors within their stories. Then I asked them to think about how they could make their experience visible to the community through a creative arts project. Their definitions of strength and creativity expanded exponentially as the projects evolved. Each participant's contribution to my understanding of creativity and caregiving influenced my approach to organizing their projects and the final exhibit. This chapter introduces the reader to the individual caregiving contexts and provides a framework for walking through the exhibit (chapter five).

4.1 Ren

Ren on creativity:

> *...inventing something because I, I am always inventing something. (Laughing) Little things that I am doing, I create different things that I am happy doing, it could be embroidery, it could be sewing, it could be making stuff.*

Plate 2 A placemat Ren made for her husband prior to participating in the study.

4.1.2 Meeting Ren

Ren and I met at a local support group for caregivers. When she called to arrange an interview, she said she was caring for her husband, who was living with dementia in their home. When we met for the interview, Ren informed me that her husband had recently moved to a care home and had passed away shortly after. Ren insisted that it might help other people and herself to remain in the study, despite her recent loss.

I sat down with Ren in her kitchen, and she generously offered me a cup of tea. My voice recorder lay at the edge of the table opposite to where she sat. In a birdcage sat the family pet bird, chatting and chirping away. I began by thanking her for being open to interviewing, having just lost her husband. It was a special gift to be sitting across from her and hearing her story.

Ren, 74, had received her husband's diagnosis five years prior. She cared for him on her own, and she took upon herself the full responsibilities of daily care: meals, personal care, driving, upkeep of their home, social activities, maintenance of their friendships, communication with their children, and self-care. The level of care Ren provided included more than the most basic needs of her husband. She had to find ways to work with his perspective in order to complete otherwise simple tasks. Ren expressed that it was difficult to leave the house because her husband wanted her near him at all times:

> *He was shadowing me for at least two years or maybe longer. If I would go downstairs he would follow me, come up.*
>
> *He just did not want anyone to take my attention; that is how attached to me he was. Every moment of his life and that is why I found it so hard. Taking him away from me, separating him from me, you know. So hard.*

Ren worked hard to stop her husband from worrying. She noticed that if one or both of them had to go somewhere the next day, it was stressful if he knew about it beforehand. Instead, she would only mention it as they were getting ready to go. The level of care Ren provided was not visible to family outside of her home. She did not want them to know for fear that they might worry about how much she was doing. Ren also wanted to preserve her husband's dignity. She could not handle the thought of someone who did not know him providing care. Ren talked about the crossword puzzle as an indicator that things were changing:

> *…he was a great person to do the crossword puzzle. He used to take that paper, and before I had a chance to look at it, he would have the crossword puzzle done. It got to the point where he would have to ask me questions, and that was good cause that got me into doing the crossword puzzles.*
>
> *Then I started doing them. It got to the point where I started doing them, he could not, but sometimes I'd ask him a word he could not spell, you know one or two.*
>
> *Then I'd say, what is a four-lettered word for some ungodly word I had never heard in my life, and he would tell it to me just like that. And I would say "Well, gee how did you know that?" but he had no idea then what I was asking him.*
>
> *So, you see what it is like. It would come through as plain as day, and that happened so often, I'd be doing a crossword puzzle, and I'd always be asking right up until he stopped doing them, I would still ask him, you know, what is that, that, that.*
>
> *So then, I would sit here in the night like after I'd say Saturday with the crossword puzzle, and I'd get him involved, and I would be asking him even when he did not know. I would ask him, "what do you think that is now?", and he would be trying to think. I always felt that when he had to think about something it was painful. Yeah, it got painful. Like it was too hard for him.*

Ren can identify how having an activity that she and her husband did together helped her to cope with and understand the transitions imposed by dementia. She gave other examples of coping with change as well. For example, she figured out that as long as the car her husband still believed he drove, was home, he would stay still long enough for her to do something or go somewhere. When it came to his bathing needs, she figured out that putting the shampoo in his hair before he stepped into the shower made things a lot easier. Not only did Ren find ways to manage the care of her husband, but she managed her well-being as well. Ren told me that the ability to get out of the house and to go running was a significant part of how she coped.

4.1.3 Ren's Creative Inventory

I think I could do it…I always thought I could do it. (on carpentry)
I am very interested. I never have the time to do it. (on painting pictures)
All the time, I would do that when I was sitting down with him. (on colouring) *I have an interest because I want to learn to play the accordion. My daughter bought it for me, and I have a book in there, and I try to play it for him.*
I used to bring my bag every day, I would sit down with him, and I would do embroidery. This is my bag and all my stuff in here. My grand-daughter gave me this little purse, so that's what I put my threads in.

[Comedy] made us laugh and got us through everything.

I cut up these old beads, and I stick the beads on. My God…and this is my sewing machine…I come down here to sew. So I never stop. The day is never long enough. Never enough hours in the day for me.

It is a good past-time and a stress relief

Involvement in the arts, for Ren, meant an opportunity to laugh and to pass time, a chance to bring together the family, and a stress-relief activity that facilitated life-long learning. She showed interest and confidence in arts activities that she had not tried before. "I think I could create some great pictures", she said concerning painting. As Ren read the inventory aloud, her voice filled with enthusiasm. She was interested in trying new things and told me about multiple creative hobbies. Ren spoke about her creativity as something she would engage with more if she had more time. After going through the inventory, Ren showed me placemats she made from family cards she collected. She had collaged them together for her husband to look at while he ate. These placemats brought her comfort, as she was able to revisit the kind words on them repeatedly. She also showed me her embroidery. Ren embroidered winter scenes, children and flowers. Then Ren walked me downstairs to show me her shrine to Elvis while looking for the

Christmas ornaments she made. The more she talked about her creative hobbies, the more she had to show me. It was as though her creativity was unraveling from a tightly wound paper scroll.

4.1.4 Ren's Initial Read-through

Ren expressed her strength by finding ways to keep herself and her husband busy. She saw the activities that had to change and found ways to adapt. She used her creativity to do projects for herself and her husband. She also used her creativity to navigate through the unpredictable days imposed by dementia. Ren demonstrated strength through her ability to navigate through transitions and develop strategies to manage caring for herself and her husband. She gathered much of her strength at home by making sure she got to run often.

Ren used her creativity to help her husband participate in daily tasks but also to maintain independence and dignity. When Ren discovered her husband was having difficulty washing his hair, she changed the sequence of events to make things easier and thus comforting him at the same time. Ren tended to her emotional health by piecing together sentiments of loving memories. She found meaning and purpose for things that other people might toss or put away in a box.

4.1.5 Ren's Creative Project: "As the Curtain Closes."

Ren described dementia as "…a window that opens and closes". She used this metaphor for her creative project along with the crossword puzzle theme and her desire to write poetry. I left Ren with a copy of her interview transcript. She told me enthusiastically that if I could give her two weeks, she would have her project finished.

When I phoned her a few days later to ask what materials I could pick up for her, she said she already had the materials, and they were mostly from around the house. After two weeks, I returned to Ren’s home to find her creative project completed.

4.2 Rhona

Rhona on creativity:

I cannot even draw a straight line unless I have a ruler

Plate 3 Rhona's recipe books.

4.2.1 Meeting Rhona

Rhona is an 85-year-old woman who cared full-time for her husband in their home. At her request, the interview took place in their house at the dining room table. Rhona's living room was cozy with a piano next to the dining room table and a little dog who showed his loyalty by sitting on her lap each time she sat down. Rhona noticed that when her husband's dementia progressed, her dog stayed close to her. Rhona told me stories of how dementia affected her and how she dealt with it. She told me about her love of baking and making up new recipes. She appeared proud when she told me that a local bakery uses her recipes. She said that she gave most of her baking away, except for what she made for her husband. For Rhona, baking was something that helped relieve her stress. When she was feeling stressed she would encourage her husband to play the piano and she would use that time to bake. If her husband forgot that he had already sat at the piano, she could sometimes encourage him to play again, giving her more time to bake. This additional time was something Rhona experienced as an extra bit of relaxation. She showed me her giant collection of recipe books and explained that she sometimes took a recipe and changed something in it, to see what happened.

I sat with Rhona at her dining room table for three hours. I drank an entire pot of coffee and enjoyed the sweets she brought out. Rhona wanted to know my story and what interested me in this research before she shared her story. The interview felt more like a conversation between relatives. Rhona told me she was exhausted and that her health was suffering because of being overwhelmed from caregiving. She was taking care of her husband full-time with small "respite" breaks, where she availed of a local service that holds a day program for people with dementia. On these days, however, she was hardly resting. Her one activity of self-care was to get her hair done. Most days she would get groceries, go to the bank and schedule or attend doctor visits. Rhona also spent a lot of time baking and sharing it with the community. Rhona's support network included her church family. However, when her husband stopped attending, she then stayed home with him on church days. Rhona's daughter, a nurse, helped her to anticipate some of the possible changes she might come across. This meant she was able to somewhat prepare for a stage where she would no longer be able to care for her husband. Near the end of our conversation, Rhona talked about the influence of the moon on her husband's behavior. She said he became very agitated and aggressive when the moon was full. The moon gave her a small element of predictability in her husband.

4.2.2 Rhona's Creativity Inventory

I am always writing letters and recipes
Singing. I used to sing in choirs, but now I cannot even hold a tune, and that is because I do not do it anymore. It is just as simple as that. My vocal cords have just…I cannot even hold a tune to sing a hymn anymore. Oh I love it. I love it. And I love listening to it and oh if I only had a voice like her and [he] would say to me 'It is just that you have not kept at it' and it was really stupid because I could have been in singing when he was playing the piano…but I would rather take the cookbook and let him play and get the enjoyment out if it.

I am 83 years old. I would love to, but I do not have what it takes anymore. Other things have taken my interest. Looking after [him]. (on being on stage)

[Stained glass]*…oh I love it! I just love it.*

Sewing. I used to sew. I have my own machine, but I have not done it for years. So I am going to say not good at it, although I made a dress and a couple of blouses and pyjamas. I am not good at it.
Dance, I love it, but I cannot dance anymore because of my bones.
Comedy. I love that. Going to comedy shows.

As Rhona read her creativity inventory, she spoke the words "not good at it" numerous times. I asked her in our initial interview how she defined creativity, and she said she did not know. Although her confidence in her creative self was low, she spoke of many things that involve a creative process. Rhona mentioned sewing a dress, blouses and pyjamas, she listed recipes she made regularly, some of which she experimented with. She told me that she and her husband enjoyed the creativity of others.

They would attend local children's choir performances and theatrical plays. She explained that at first, it was an opportunity to relax, and people were generally very good to them, and then as his dementia progressed, it became more challenging to go. When this transition occurred, she began to invite people over to their home in place of going out.

4.2.3 Initial Read-Through for Narrative Meanings

Rhona was able to put her needs second for many years. She demonstrated strength in her ability to find ways to continue with her day-to-day routine, i.e., baking. Rhona found herself needing to be creative to comfort her husband when he was upset. She states, “things that I felt like would upset him... you know in some way, I would find another way to get around it that way, you know”. Rhona also discusses activities that she and her husband do together:

> *We go to the arts and culture and listen to a choir and people playing. He was in his glee and tapped his hands, and the man next to him said to him, “you must be interested in music, are you sir?” So he just nodded his head. Coming home, he said, “that was a fabulous evening”. So I called [my son] the next morning and told him how much he enjoyed it, and he said, “well what about you mom?” and I said, oh yes I enjoyed it too. I even relaxed. I was not nearly as tense as when I left here to go. That is about the most relaxing and the most pleasant times that we spend.*

Rhona thought creatively about her husband’s need to play piano. This effort helped her to find time to bake. Rhona’s creativity allowed both her and her husband to maintain continuity in their relationship:

> *He still plays the piano. Does not know one note from the other anymore but you know it is a lifetime habit and a good one. After we finish dinner in the evenings we always…I get him to go in at the piano and play for…well his timespan is not that long any more, but he will probably stay there for about twenty minutes.*

Perhaps Rhona’s greatest strength was being able to tell me when she felt she would not be able to complete her creative project. When her caregiving role began to affect her health, she took the advice of her doctor to cut things out. In order to continue caring for her husband in their own home, she cut out her commitments. Rhona seems sad when she told me she had to withdraw from the study. She told me I had made her feel that it was okay to take care of herself but that she had to take care of her husband. Rhona met with me about her creative project and asked that I finish it for her. Rhona made every attempt to attend the exhibit but in the end was unable to be there.

4.2.4 Rhona's Creative Project: "Oh Moon"

Rhona centred her creative project on the idea that the moon changes everything. The themes that I chose were baking, piano music, recipe books, and the moon. These four themes represent the things that Rhona spoke about with confidence and pride. I recall standing at Rhona's window as she reminisced about standing there with her husband. She remarked that she wished she could shoot the moon down.

4.3 Forrest

Forrest on creativity:

Things I thought she might like to do and making changes. Not the same thing every day, something different, making change every day
You've got to think about, you got to realize what is in there and you have an idea, and you have got to turn the idea into something real. I mean you go and do it. That is what it means to me.

Plate 4   Piano and music. Stock photo.

4.3.1 Meeting Forrest

Forrest was 94 years old when I met him. He sat with me in his home and told me about caring for his wife who had passed away 16 years earlier. They were married for 49 years. Forrest called me for an interview, and I remember him saying after he introduced himself, "If you want to know about caregiving, I can tell you all about it." Indeed, he told his story as if it had happened the day before. In his interview, Forrest described how their lives had changed with dementia in the picture. He organized care for his wife so he could care for himself as well. One of the ways Forrest did this was by arranging for paid caregivers to come to the house to help with his wife's daily care requirements. He would also have someone accompany him and his wife on a trip to the cabin. Later as the disease progressed, he continued to visit the cabin alone. Forrest spoke with pride when he told me about arranging his wife's care. He knew the importance of taking time for himself to recharge. It was important to him that she remain in their home until her last breath, and she did. Forrest always made sure he took time for himself, so he had the energy to care for his wife. For Forrest, his creativity shone through in decision making. As he spoke of all the places he and his wife had been together, and where he continued to go on his own, and where his support came from, I visualized a map with markers of self-care.

4.3.2 Forrest's Creativity Inventory

As Forrest read the creativity inventory quietly to himself, he stopped to reflect on singing and songwriting. Forrest wrote numerous songs when he was in the Navy. Despite his pride in what he wrote, his songs were not something he shared with others but rather something he did for himself. I could hear in his voice that his music continued to be important to him even though he no longer writes. He spoke with pride when he told me that his daughter wanted him to do something more with his music. Forrest began to sing a few lines that he wrote from one particular song: "…When somebody's boy is out to sea, in the waters and he was free, somebody's body" He said, "songs I used to write, you know. My voice is gone. I cannot sing. I used to love to sing for hours but now I never do it." Forrest referred to his health issues as taking away his ability to enjoy music. He experienced a similar loss of being able to go dancing due to his wife's dementia, "I used to go dancing every other weekend with my wife before she got sick."

Although the inventory prompted Forrest to talk about his loss, he also began to think of alternative ways to enjoy music. He asked me if I sang and when I told him I did, he suggested we make some music together and invite people to watch. In talking about the creativity, he felt he was no longer able to do, he showed emotion and expressed the desire to have that element of his life back.

4.3.3 Initial Read-through for Narrative Meanings

Forrest emphasized the importance of taking breaks and travel. He found that going away with his wife in the early years, and then on his own when she could not travel, was an opportunity to re-charge. Forrest had a proactive approach to support. He reached out early and arranged to have regular help with his wife's care. Because of the extra support, Forrest was able to maintain some pieces of his relationship that he was not willing to lose. He was also able to establish a routine early on that prevented him from shouldering care-responsibilities all on his own. Forrest created a network of care in his home and his community. He paid attention to the things he and his wife would do together before dementia was a part of the picture and took steps to make sure it was still a part of their relationship. Forrest gave examples of watching a show, going to the cabin, playing piano, or going dancing.

4.3.4 Forrest's Creative Project

Because Forrest had mentioned many different place names in Newfoundland, I brought a map to our second meeting. He and I discussed using different coloured threads to illustrate the network he had created throughout his journey through caregiving. Each place he spoke about on the map would have a similar story.

Due to unforeseen health concerns, Forrest asked if he could contact me when he was feeling better. I checked in with him after a month, and he said he was still ill and that he would call me when he was well enough to continue. I was saddened to learn of his passing not long after.

4.4 Linus

Linus on creativity:

You create the story, and you are using your imagination beyond belief.
You have got to keep the mind active.

Plate 5 Linus and I holding his completed project.

4.4.1 Meeting Linus

Linus, 43, was providing care for his mother who lives in an assisted-living home. At the time of our interview, the doctors had only recently suggested his mother had dementia. Linus hoped that by participating, he would learn new ways of coping, communicating, and understanding the context of dementia. At the time of our first interview, Linus could identify very few supportive resources available to him. He mentioned that he had an aunt who called to check in on his mother on occasion. Linus told me his mother experienced paranoia and that he found himself frequently reassuring her. He knew that things had changed when his mother began to ask him the same questions repeatedly. Linus told me about living with Tourette's syndrome and the kinds of challenges that added within his caregiving role.

4.4.2 Linus' Creativity Inventory

For ease Acrylic, but for sense of accomplishment…oil. (on painting) *Painting with Tourette's is a real challenge.*

I love comedy too. I may not be funny, but it is so subjective. But I love watching anything comedy, and I try to be hilarious myself sometimes.

Linus read through the inventory and commented that he had interest in multiple creative activities. His energy came alive when he spoke about being on stage and he made a direct link between his experience of his health and acting:

> *That is my first love...acting. A by-product of acting was a surprising thing, where when I was on stage, I had no ticks for my Tourette's. It would just go away. I never really noticed this until someone brought it up. But I loved acting a lot.*

Linus' engagement with the creativity inventory also revealed that he had taken painting classes with a well-known local artist. He writes, paints, sketches, and builds miniature game figurines. Linus also enjoys writing, although he said it was more his mother's talent (she is a published playwright). Linus talked about the lack of Tourette's symptoms when he was creative.

4.4.3 Initial Read-Through for Narrative Meanings

Humour is a significant part of Linus' strength. Linus used being funny as an aid in tense situations or trying conversations with his Mom. Stress significantly impacts his wellbeing, but he was eager to find ways to deal with it and express his feelings. He told me of one context where he sang his frustrations in an operatic voice as a way to diffuse tension in the room with his mother. We discussed his desire to try new strategies. He spoke with pride about his ability to let go of expectations so he could better communicate with his Mom. While he was overwhelmed with the change in parent-child roles, he also showed strength in embracing his new responsibilities. For Linus, laughter allowed him to dissipate feelings of anger. Laughter provided a therapeutic effect for him and his mom:

> *That [laughter] helps because I am also really quick to temper…there are these times when I am trying to deal with mom's rage. I've got to deal with mine because she cannot help it, I can.*

He explained that:

> *To do that, I try to think of something funny. I try to imagine Mom in a ridiculous situation. You know, her trying to shop and her running into Lou Abbott and Boyd Costello and this slapstick talking about who is on first and like playing on her lack of memory, so it keeps going around in circles, and I find that intensely funny.*

Linus' experiences highlight how creativity provides an outlet for the emotions involved in caring for his mother, and it brings visibility to those emotions.

Linus illustrates,

> *I did some poetry. I have not done poetry in a while. I did a lot of poetry. It is…I actually really love doing it. A way of getting a moment of feeling on paper. What you are feeling at the moment….capture this now*

4.4.4 Linus' Creative Project: "Full Circle"

Linus' project involved a poem, painting, photographs, and a comic sketch on canvas. After finishing these pieces, a year later, he also wrote a short story. Months after the exhibit he said, "I realized that the short story had the potential to be just one chapter in a book. I will write it until she dies and then it will be finished. It seems right somehow” (Email correspondence five months after the exhibit).

4.5 Amelia

Amelia on creativity:

To conceive something. You do not even have a brush in your hand, and you are conceiving it.
I am a storyteller.

Plate 6 Amelia trying on hats she made for a craft sale.

4.5.1 Meeting Amelia

Amelia heard about my project through a mutual friend. She called and invited me to come to her home for tea. She told her caregiving story from beginning to end, leaving little room for the formalities of even a semi-structured interview. She told me about how she cared for her husband, who was on sick leave for most of his life. In addition to caring for her children, and in the context of dementia, Amelia also cared for both her sister and her mother. Amelia always worked and sometimes held several jobs.

4.5.2 Amelia's Creativity Inventory

I love to sing, but I am not good at it

Dance that is a real interest of mine.
It would be nothing for a song to go on the radio, even the last four months before he died and he would grab me, and we would go around the living room and dance
My body responds to music and dancing. That is something that I do.

Amelia’s definition of creativity says that an individual must be able to come up with the original idea and not just follow a plan. Amelia defined creativity and being an artist in the same breath with no distinction. As she read over the inventory, she evaluated the items based on interest or no interest until she came to an end. She said she had an interest in writing, but in the end, she said “I think I should also say another one here too, because I sell hats”. In our interview, she only briefly mentioned that she made wool felted hats. She invited me to see her at a local artisan show. I was surprised to see close to a hundred vibrant wool hats lining her stall walls. Amelia encouraged me to try some on. She tried some on herself. Her spirit was positive and energetic in the company of her hats.

4.5.3 Initial Read-Through for Narrative Meanings

In my second meeting with Amelia, I drew her attention to the multiple people she had cared and continues to care for. These people included her husband, her mother, her children, and now her sister. She spoke with confidence about her work as a young feminist and as an experienced caregiver. In the following quotation, she demonstrates her creative thinking as she finds a way to bring her sister into her creative process. When Amelia noticed her sister acting restless, she designed a task that allowed her sister to feel included and useful:

> *I knit wool hats, and they have to be pure wool. So I had a sweater that I was raveling, so I said I am going to ravel that sweater and knit a wool hat out of it.*

> *Because it was really good wool. So one day she came in, and I thought, I got to find something for her to do now. She wants to do something, and she can't do it. This is continual, and it is like being on stage or deck for seven or eight hours. I get tired of doing the same old dance. So I got her in there and got it set up so she could pull the wool, and I could reel it. She could pull the wool and I could reel it and so on.*
>
> *Then I get her, if she is going to be here for two meals on Sundays, then I get her to peel the carrots. I am getting her to do something, so she feels worthwhile.*

One of Amelia's strengths was her capacity to see the importance of purpose. Whether caring for her husband, her children, her mother, her sister, or herself, she thought of activities that encouraged contribution and self-worth.

4.5.4 Amelia's Creative Project: "I am my Hat"

When I thought about all the different care roles she had played, I knew the hats would be a part of her project. Amelia used the metaphor of a shelf when talking about her hats. She said there was not always room for all of one's hats on the shelf. She decided on three and attached labelled tags to three different sized and colored hats. Amelia designed the hats, made them, and then wrote on the tags.

4.6 Isobel

Isobel on creativity:

Creativity…it may be an expression of yourself as a way of giving to people

Plate 7 Wooden boat (by Glenda's father) and a hooked rug of her mother's summer home.

4.6.1 Meeting Isobel

Isobel is a mother of two young children and cares for her mother who is living with dementia. She works full-time as a nurse and finds it quite overwhelming to be providing care for her mother and her children. Isobel is always caring for people in her work life (as a nurse) and in her home life (as a mother and daughter). In her interview, she told me that her mother is mostly blind. Isobel told me of how her mother began to put things in soup that were not supposed to be there. She thought it must be a mix of dementia and poor eyesight. Her creativity allowed her to find things for her mother to do that make her feel useful. For example, her mother has always liked to darn things. Isobel said she does not notice what she is darning, but enjoys providing that skill, so she will give her mother old pillowcases and socks (things that do not necessarily need fixing), but tasks that help her mother to feel a sense of purpose and contribution in the family. Her parents live together in their own home. Isobel brings them meals regularly. She said that one of the more difficult things is being able to clean her parents' home without her mother noticing. Isobel is careful to respect her mother's pride in "keeping house" even when she can no longer keep things clean. When her mother received home care, Isobel brought her mother to the family home she loved during the summer months. It is pictured in the hooked rug above.

4.6.2 Isobel's Creativity Inventory

Writing…I do like to write, I rarely do it now…singing is a definite interest.

My mom, years ago, flour used to come in years ago in bags, cloth bags. My mom would always keep those and make table cloths out of them. She would crochet around the outside of them and then either do a design…she has flour sacks that she has our handprints on, and she embroidered those. She traced with pencil and stenciled with embroidery…

This is support for me too. Honestly, anytime I can purge, and I do not know if that is what you find with other people, but you cope by purging. The demands of every day keep going no matter what.

For Isobel, creativity is "productive." Being an artist falls "…along a great big long continuum of something." She explains that this could mean anything "from making practical things to expressions of statues and monuments that are trying to explain something". Isobel's articulation of creativity points to its purpose. Being an artist means being creative to produce something practical or something to communicate a message, and sometimes both.

Isobel has participated in the arts through her children's interests, but she has also sung and played guitar. She told me that she had not done anything creative with her music in a while. She and her mother would sing and play "The Dutchman," which is a significant piece for her as it is about dementia. Initially, Isobel's creative project would be to sing this song with her mother. The project would serve as a way to get back into her music and to spend time creatively with her mother.

4.6.3 Initial Read-Through for Narrative Meanings

Isobel's initial read-through showed that she thinks quickly about how to make tasks for her mother to do. She also gives her mother plenty of time with her children, because she identifies this as one of her mother's strengths (interacting with the grandchildren). Isobel spoke of how her mother has very little vision. Because of this, Isobel has had to be uniquely creative in finding things her mother can do that make her feel useful. Isobel's mother took old rags and darned them, as if she was repairing beautiful blankets. Isobel says,

> *…she has never thrown anything away. There are blankets that we would have torn up and used as floor rags that she is repairing. Of course she can't see, so she is darning…they are in terrible states, but she is very proud of what she's done.*

Isobel explains that making up tasks for her mother also helps to try to keep things regular. Isobel would engage her mother in daily activities including peeling vegetables, so she was still a part of the meal-making process, darning, so she was still able to feel helpful, and even putting family names on potato sacks to engage in kin-keeping. One of

Isobel's biggest strengths is her ability to see alternative ways to do things. As a caregiver, she uses creativity to help her mother enjoy hobbies that maintain a sense of identity. Isobel also speaks of her mother's identity with reference to poetry and music:

> *Other things that she would do is write poetry. She still writes poetry. If there is a reason…my daughter's school was closing, and she did not understand that, but she wrote her a poem about leaving school and things like that….she cannot fully understand the concepts at times, and wrote her a poem that was appropriate for a leaving school as if you were leaving all your friends. So she will still sit and write poems.*
>
> *…music helps her be herself. So I would say keep the things that you appreciated as a younger person involved and try to keep your normal life going as long as you can.*

4.6.4 Isobel's Creative Project: "Things are Changing"

I left Isobel with the transcript from her interview and met with her again a month later. She came to the meeting with a fresh new idea. She decided to take a song she loved, change some of the lyrics to describe her relationship with her mother, and sing the adapted song without any accompaniment. She created a slideshow of images to accompany her vocal track. Isobel and I were not able to meet often or for very long each time, but when we did, she had a fountain of ideas for moving forward.

4.7 Annie

Annie on Creativity:

I think a creative person can be a problem solver and an innovator. A creative person has a very open mind. It is not all locked. A creative person has insight, is very expressive in perhaps individually different ways. Sometimes a creative person can take a situation and shift it into something new, different, and better.

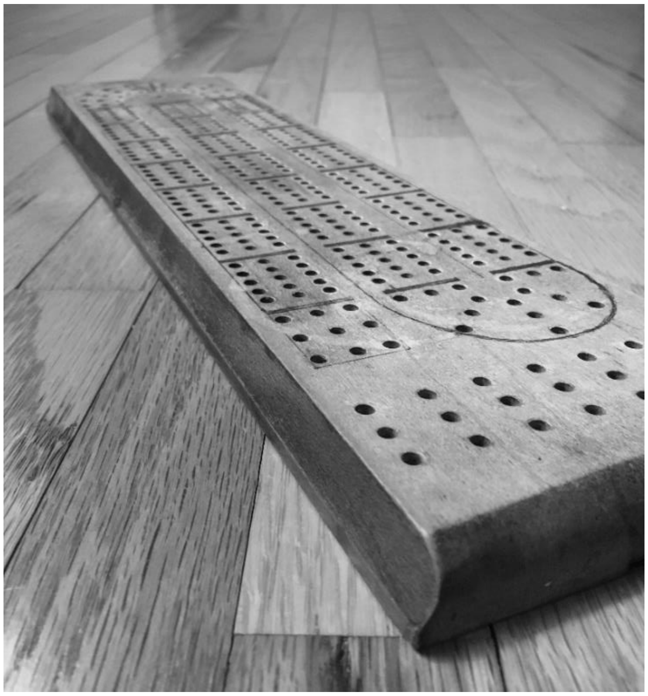


Plate 8 Cribbage board.

4.7.1 Meeting Annie

Annie cared for her husband, who had passed away a few years before our interview. She withdrew from the research before the creative project began as she felt she could not continue with it. She explained that someone close to her had just found out she had dementia and that it would be too difficult for her to remain in the study. Annie was full of enthusiasm in her interview. She demonstrated profound creative strength. She cared for her husband in their home, and she had some support from a man who moved onto their property and did most of the driving. Annie said that she had attended a support group for caregivers; however, it only made her feel sad. She said that if she had some free time, she would rather spend it doing something positive like going to a movie, rather than hearing about sad stories of a person's week.

4.7.2 Annie's Creativity Inventory

I was in the quilter's guild for quite a while, but I mostly make everything on my own. You could get somebody who did calligraphy. You could make a beautiful chart. Have you ever heard of putting a list of things in a jar or a bag and a list of things you need to do. You write them all on scraps of paper or however, you want to do it, and then you put them in a jar and then pull one out. It could be quite beautiful. Suggestions or thoughts…

I think moments are all you can do. But you can do a lot of manipulating around that idea. I never thought about that before.

Especially when we got into the lightness, lightening things up. Things can get pretty heavy if you can throw in some fluffies.

Annie told me about how she pictured a box with different activities written inside. The activities would not require too much attention for too long and would be enjoyable for both caregiver and care-receiver. Annie considers herself a creative person and engages in multiple artistic projects. She is a skilled painter and works with fabric and sewing. Annie's story continued to develop, and although she withdrew before the creative project, I have included her story as a way of sharing her strength. Annie was able to do something creative while caregiving that she credits as providing self-care. Annie was able to turn down commitments that do not make her feel strong (such as support group discussions) and take opportunities to re-charge (for example going to a cabin). This kind of self-knowledge, self-preservation, and strength is exactly what creativity encourages. Annie explained that having dementia meant her husband was "losing all the maps in his head". Annie explained that understanding dementia through brain function made it less emotional for her when dealing with change. Annie, similar to Linus, found that visualizing her family member in a funny situation released frustration:

> *The anger needs to be dispersed in another way. There is a lot of anger that needs to be dealt with the funny things that can happen, like [my husband] going down being Johnny apple-seed. That's one of the things I remember with humour because it was so sweet. I think there are so many supportive things that can happen if one were exposed to learning about them.*

Annie envisioned her husband as a character that she enjoyed. She linked between humour and coping with dementia. The creative visions that brought laughter to Annie's thoughts allowed her a more positive perspective on some of his behaviors. Annie maintained continuity through finding ways to do things they had always done, differently. During our interview, Annie brought out a cribbage board with lines and arrows on it:

> *I still have the marks on the cribbage board. He could not figure out which direction to go in Cribbage, which we had played for years. So I had to put the marks and which way to go.*

Annie talked about being creative to bring spontaneity and joy to an everyday activity:

> *So you are going to take your husband for a walk, but you could have also been preparing a surprise picnic with little things to open up as well. You know. Supposing you told your person you were going to go for a walk, but then you go*

down to Bowring park and you open up your hamper and it could be anything from blowing bubbles etc.

4.8 Jack

Jack on creativity:

We are, to some degree, a product of our memories and if you have lived with someone, husband and wife, in our case for over thirty-five years, you have an enormous number of shared memories. But once the Alzheimer 's disease starts to take place, your memory paths begin to diverge. The last portion of her memory with me is different from mine. Apart from the fact that we are two different persons, The reality diverges and I found that, as I say, easier to cope with.

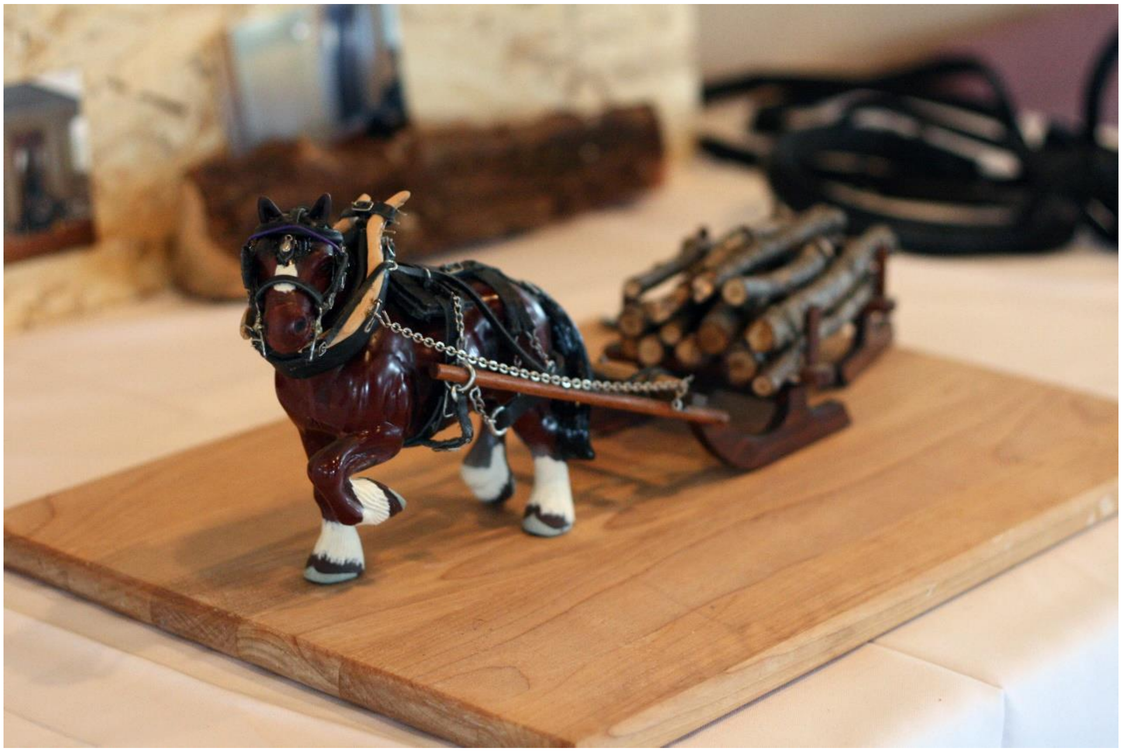


Plate 9 Miniature riding gear made by Jack.

…whether it be a new piece of music, a new piece of art, a new piece of sculpture, a new woodworking project…altering the house, even repairing stuff. You see something that is broken and you have got to think, now how can I repair that?

4.8.1 Meeting Jack

Jack contacted me quite late in my projected timeline. He was living outside of St.

John's and as I was eager to hear a story from a smaller community, I welcomed his request for an interview. We held our initial interview by telephone but then met in person when he next came into town. Jack had been caring for his wife for seven years. He went to the assisted-living home where she was and ate with her every day. In the beginning stages, Jack and his wife actively engaged in sharing their expertise with the Alzheimer's society. They wrote and presented their experience and what they had learned and shared advice on how to have strength in similar circumstances. Jack spoke about his love of horses. He described how he and his wife's ability to ride evolved over time. Riding horses was something they could do on their own or together for many years but as his wife's dementia progressed, Jack began driving a horse-drawn carriage. She sat beside him so they could continue to enjoy riding together.

Jack explained that becoming a caregiver meant learning to do what his wife had always done. He stated,

> *It meant, really, a complete reversal of roles. My wife was a nurse, a midwife, and a massage therapist and her whole life was geared towards caring, and she always was the person who cared for our children, for me, and for all sorts of other people through her own professional life. It meant I had to take on these roles, which I had really never considered before. I never sat down and thought, 'oh my god, I have got to look after a colostomy'. I never felt overwhelmed by them until right in the latter stages where we had to seriously consider long-term care.*

Jack highlighted that there is no day-to-day predictability and so one cannot make decisions confidently. He explained that tasks such as cooking or bathing, which allowed independence for his wife could no longer be her responsibility. Jack had to find ways to help without taking away what those things meant to her. From the beginning, Jack did whatever he could to keep his wife involved in the decision-making concerning short and long-term living arrangements. Jack attributed being part of a local community group in his area as a significant source of support and spoke highly of his children and their support as well. They demonstrated their support by being there for him physically so he could leave the house, and, emotionally being there, so he felt support for his perspective and consequent decision-making.

4.8.2 Jack's Creativity Inventory

I have done one or two collages.
I have been a member of the choir here and quite enjoy that.
*I have never tried it, but it is something that I might one day. (*on stained glass) *I have been a member of the amateur dramatics here, but I am always backstage, stage manager, that sort of thing.*
Comedy. I like to watch it.

Jack's engagement with the Creativity Cue prompted him to think about the things that he and his wife enjoyed doing together. He then described to me the difference between losing your partner and losing a parent. He stated,

> *…It is not the same as having lived closely with someone for thirty-five or more years, and then finding that you are losing them and that there is nothing you can do about it. And you do not have your partner to talk to about it. I think that is the thing that I miss most. Any other disease virtually, you would be able to talk to your partner about it, and the two of you could be involved, even if it is something as disastrous as Cancer; it is something that you can talk to with your partner whom you have known for all these years. With Alzheimer's disease, your partner is gone. That is I think the huge difference between it being your partner and it being a parent.*

Jack's creativity became apparent when he showed me picture after picture of renovations he was doing in their home to adapt to living on his own. He envisioned a different layout and made a plan. Then he began to take down walls. The photos demonstrated that every step was meaningful to him. We had a lengthy conversation about how the changes he was making to the house were symbolic and provided a metaphor for his adjustments to the progression of dementia and his experience of transition.

4.8.3 Initial Read-Through for Narrative Meanings

Jack and his wife were actively involved in educating their own family and families in communities across Newfoundland. Jack showed me a presentation that he developed on how to deal with a diagnosis and what comes afterward. One of Jack's greatest strengths was his ability to see purpose in his experience, beyond his context. Jack researched his questions, found community support through a local organization, and became an advocate of what worked for his family. He presented his experience with humour and concise practical tips on making things easier and even enjoyable. He stressed the importance of maintaining a loved one's involvement in decision-making, a social life, and finding relaxing activities to do together.

Jack's strengths involved being able to manage a routine and design fulfilling projects. He accepted the re-definition of his role in his relationship and altered the routine so he could keep some things the same. Jack decided to remodel his house because he could envision something different for himself. When his wife was no longer sharing the bedroom, he wanted it to be his room. He would go to eat a meal with her every day, and sometimes bring her out. One of his most obvious strengths was his capacity to adapt to change and make the new context equally meaningful for him and his wife.

Jack found a way to share his experiences through the Alzheimer's Society by giving presentations on what worked in his relationship. He maintained her presence through photo and quotations even after she was no longer able to attend physically. Inclusion is not the mere act of bringing someone along but finding a way of involving them, so they feel they are a part of something. Jack was creative in finding ways to give his wife a chance to relax, continuity in their identity as a couple and involvement in activities they had always done together.

> *I have a couple of horses. I drive a wagon or a sleigh in the winter, if the weather is suitable. My wife used to come down, and we would go out for a ride in the horse and wagon. That was really nice and relaxing to be able to get out. (spouse's name) would go swimming with this friend of hers. At home, as long as she was able to, when she got a little more housebound we were able to watch movies together. We used to play cards. Anything really, to try and keep her occupied and active.*

Jack explains how maintaining continuity can also involve providing comfort:

> *She had difficulty cooking, and I slowly had to take over the cooking, which was difficult for her. It was quite a fine line to decide whether I should do at any time, because, again, anyone with dementia has good days and bad days, and sometimes they can do more and sometimes they can do less. There is no way of foreseeing on one particular day how they will be. So I had to decide whether I should do the cooking and risk upsetting my wife – because she had always done it and she wanted to do it – or allowing her to do it and her getting upset because she could not manage. I found that quite difficult to do.*

4.8.4 Jack's Creative Project: "Keeping the Faith"

Jack's creative project involved many photos. Renovating his house was something he decided to do to make his home more comfortable after his wife moved to an assisted-care home. He took photos of bare wood stripped of outer layers. He took photos of tools and piles of building materials. He took pictures of the foundation and the walls coming down. Jack did not just document the before and after of his renovations, but the entire process. Jack and I discussed how he was building a metaphor for adjusting to the changes imposed by caring for a loved one with dementia.

One is continually adjusting things, problem-solving, being creative with a vision of what things should look like, and letting go of how things used to be. For his creative project, Jack included a printout of a presentation he and his wife wrote about Alzheimer's disease.

4.9 Tavish

Tavish on creativity:

I am just not. If I want to draw a straight line, I need a piece of paper and a ruler to do so.
There are alternatives. You just have to figure out, Okay, what's the alternative to doing what you used to do. You can't do it the same way you did it for years, but what's the alternative? What's another way to do the same activity?

Plate 10 Tavish and his wife watch the fireworks.

4.9.1 Meeting Tavish

Tavish contacted me from a small town in Newfoundland and asked to participate in my project. We corresponded over email and I travelled to his town to meet for an interview. His interview was a unique experience for me because his wife, who is living with dementia, sat beside him during the interview. I would soon learn that this was his greatest strength, always allowing her space beside him. Tavish sat confidently beside Carol on their couch and held her hand. He informed me that he would not be using her name, but instead would refer to “her” and “she” to increase his wife’s comfort during the interview. He told me that her mother had lived with dementia and so it was a familiar story to both of them. It was so familiar that in fact Carol would assume we were talking about her mother. When Carol asked, “who are you talking about?” he replied, “not you dear” or “your mother”. I have met people with different stages of dementia, and people who work and care alongside them, but never have I seen two people with this pair’s dynamic. I tried to find a way to describe their dynamic in plain text. The following text is an excerpt stripped of Tavish’s talking to me, but showing his constant loving interaction with his wife during our interview. In between their dialogue, Tavish told me of his experience caring for his wife and about their life before and after dementia. The dialogue below repeated several times over an hour and a half period. The two voices speak slowly and calmly to each other without any annoyance or frustration.

You talking about me?
No, talking about me now.
His mother he’s talking about…This is me, by the way…You’re talking about me No,
we’re not, talking about your mother.
This is me, by the way…You’re talking about your mother, aren’t you?
Uh-huh.
You’re talking about me, are you?
No we’re not.
You’re not talking about me though, are you?
No we’re not.
You talking about him?
Yep, we’re talking about me now.
You’re not talking about your mother though.
No, your mom.
You’re talking about your mother though.
Yes.
You talking about me? You’re not talking about me, are you?
No. Your mom used to do these things.
Are you talking about me?

No
This is me, by the way…You're talking about your mother are you?
Yes.
Me?
Yes, you. No, your mom.
You're talking about your mother though.
Mm-hmm.
Are you talking about me? Yeah,
you.

Tavish's creativity was directly visible in his wife's demeanor. She exuded confidence even as she stumbled on finding words. It was clear she felt assured by his side. He told me that every part of caregiving required a different perspective. Tavish maintained an assertive and pre-emptive approach to caregiving and looked for inspirational literature. He read about leadership and management and decided that he needed to have a plan that would be adaptable to transition. He said that in the beginning, he noticed that out-of-the-ordinary behaviors became more frequent. He stated, "the magnitude of them became greater. Therefore, it was obvious to me that there is an issue here. It took eight months to convince her to go to the doctor." Tavish did a lot of searching for support and information online. His approach was to say "Okay, now we have the problem fairly defined. Now let us go and manage the solution. How are we going to manage our lives, our time, our family interactions, etc.?" He expressed that relearning patience was one of the most difficult transitions. When he figured this out, he began to strategize, to become a creative caregiver. He found ways to help his wife maintain dignity and independence in her day-to-day activities and enjoyment of life. He printed cards to give to staff on airplanes or restaurants etc., so he could quietly thank them for being patient with his wife as she was living with dementia. One of the most significant statements that has stayed with me since our interview was hearing Tavish say, “We have given up very little.”

4.9.2 Tavish’s Creativity Inventory

I am not good at it, plain and simple (carpentry)
No interest (quilting, collage, painting, drawing, writing)
Definitely Not. (singing)
No. (instruments)
*I have some interest in that since I do things periodically. (*building)
Now, I am going to say cooking is a hobby with me, because I love to… I have actually become a reasonably good chef It has become a hobby now. (comedy)
…you do not have “passion” on here! (skiing)

Tavish talked about creativity in the form of what it means to be an artist, which he said he was not. Tavish explained that his wife did many crafty and artistic things and proceeded to show me her paintings and such around the room. At one point, he stated, “I am just not – if I want to draw a straight line, I need a piece of paper and a ruler to do so. And even then I will probably check it to make sure it is straight”. For Tavish, the act of creating something requires structure, tools and quality checks. These things are *his* requirements to be creative, although he could not recognize it in himself at the time of the interview. His approach to his relationship with his wife and providing her care was in fact creative, in that he was constantly making plans that required strategizing. Even as we were speaking, our interview required him to reassure his wife, who interjected regularly with questions.

4.9.3 Initial Read-Through for Narrative Meanings

“Sure, we all have our moments, but extended periods of stress? I have not felt it.”

Tavish's strategies for caregiving included thinking about an activity he and his wife enjoyed (driving) and finding a way to adapt it, so it was both longer and more productive. He planned rest stops and incorporated grocery shopping in another town. He found strength in helping his wife to maintain her independence. Upon noticing that she could not coordinate clothes but could still dress herself, he purchased a series of duplicate tops and pants where all the combinations were matches. This way, no matter what she put on, she was well dressed. Soon after our interview, Tavish sent me an email with something else he wanted to say. This was his correspondence:

> *One activity we complete together that I neglected to mention during our interview is Geocaching! We have both found this activity to be both enjoyable and a great stress reliever. We have been Geocachers for 4-6 years, and Carol thoroughly enjoys each outing! It is easy to do and possibly something you could include in your program as an interactive outlet for Caregivers. It is also fun to do as a group. Either with your peers or family members. The latter also offers excellent family interactivity for the person afflicted with Alzheimer's illness!*
>
> *Respectfully,*
>
> *Tavish.*

Tavish maintained a constant physical and emotional presence for his wife. He channeled his creativity by finding ways to reframe his days with his wife physically beside him most of the time.

> *She shadows me everywhere. Some people say, well gee that must be an awful nuisance? No. I know exactly where she is all the time. It can be, but I look at it as being positive. I do not have to look over my shoulder and wonder where you went, because I know she is right there, right behind me. So I look at that pretty positively. That will change, but until it does change it gives you some sense of comfort to know she's there.*

Tavish' wife was right beside him during our interview, throughout his art-making process and at the exhibit. Attachment is a prominent theme in his project. His photographs include an image of his feet next to his wife's. The photos take the viewer/reader along with them on their geocaching adventure. It is common for an individual with dementia to want to be near to the person who reassures them in periods of uncertainty. Tavish's video shows his wife skating and images of her spending time with their family. The titles on the screen suggest that they continue to take vacations together. Tavish identified his wife's need for attachment and thought creatively about what activities accommodate this need while also providing positive experiences for both individuals. Tavish illustrates how he finds way to include his wife in family traditions:

> *We still go skiing. She does not ski anymore, but I do. We go to Alberta – one of our daughters has a ski chalet. So it is easy to manage her time there. If we go to Clarenville with my other daughter and her family, we just kind of spell each other off for an hour. I will go for an hour, and when I come back my daughter will go. Or they will all go together as a family, and I stay in the lodge with her and have coffee and whatever*.

Tavish explained that when he felt frustrated that his wife could not remember how to peel vegetables, he decided (instead of not including her in preparing the meal) he would give her tasks to do that made her feel involved,

> *She can pass you the vegetables out of the fridge and out of the cupboard, and she can pass you a pot, and she can open the garbage can when you are ready to throw all the stuff out. We do not exclude her from these activities. She used to always do them. She still does them, but she does it a little differently*.

Another example from Tavish:

> *We go skating in the winter. Public skating a number of times over the winter. It is kind of funny – we go with the Parents and Tots now. But she will get on the ice for an hour, and she will stay out there…Okay, what is the alternative to doing what you used to do. You cannot do it the same way you did it for years, but what is the alternative? What is another way to do the same activity? You get a little bit creative sometimes*.

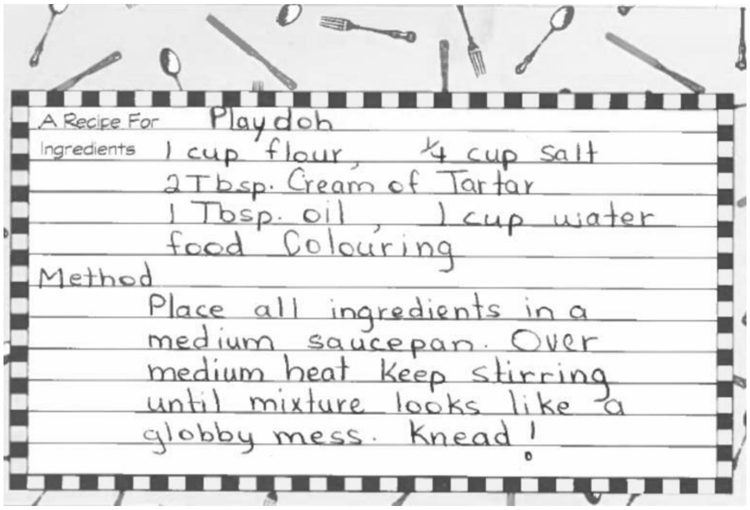
4.9.4 Tavish's Creative Project: "Carol's Project"

Tavish and I discussed what his creative project might look like. He wished to include the process of geocaching as a metaphor. We talked at length about the experience of finding your way to something, even when you do not know what you are looking for. Tavish decided that he would plan to go geocaching and take photographs that would share his experience. He titled his project with his wife's name to give her visibility.

4.10 Emma

Emma on creativity:

You have got to be crafty… so you have to do a bit of role-playing there and pretend. You take something and make it as unique as possible, or an idea. It could be abstract or otherwise and just how you perceive it, I guess. In a nutshell is just being unique, being who you are. I do not have a lot, but I probably have more than I think I do. Being creative. I like being around creative people and watching what they produce, whether it be just engaging in conversation or looking at art or listening to music. I rank myself very low in that area.



A Recipe For Playdoh
Ingredients 1 cup flour, 1/4 cup salt
2 Tbsp. Cream of Tartar
1 Tbsp. oil, 1 cup water
food Colouring
Method
Place all ingredients in a
medium saucepan. Over
medium heat Keep stirring
until mixture looks like a
globby mess. Knead!

Plate 11 Emma's recipe for playdough.

4.10.1 Meeting Emma

For Emma’s interview, she invited me to her home to hear her story of caring for her mother. Emma’s mother and father were residing together. She finds herself providing help with daily tasks such as showering, dressing, and cooking (to name a few). Emma explained that having dementia means a gradual regression of dignity and independence. She told me that providing care means dealing with the unexpected and taking more time to do simple things. Emma commented on the difficulty of continually adjusting to transition. Emma’s creativity shines in her caregiving role as she strategizes to maintain the activities that at one time gave her mother confidence. Emma explained what dementia means to her:

> *In a nutshell, it is just a loved one, someone you love very much, losing their ability to be independent…basically. Total lack of independence and dignity, and it is very emotional. I am surprised that I am crying because I think I keep it at bay a lot. I think what has happened is I have seen a progression that has been gradual, and then all of a sudden it is like jumping off a cliff. You are dealing with things that you did not expect to ever deal with, you know?*

When her mother is worried about something that is not happening, Emma finds herself role-playing or making things up to provide reassurance. A significant concept that Emma pointed out was that becoming a caregiver influenced her family dynamic. In addition to caring for her mother, Emma cares for her father so he in turn can care for his wife. Emma struggles to explain circumstances to other family members and maintain their relationships with her. Emma is also a mother, which is a caregiving role that existed before her mother's diagnosis. She stretches her creative decision-making across multiple relationships. Emma defines creativity as partly about a product or process and partly about the person. A person's unique personality can make them creative, or their skill at creating a product can also make them creative.

4.10.2 Emma's Creativity Inventory

I would love to know how to crochet but I could never, so maybe I would just say not good at it.
I do have a hobby of knitting. Now I do not knit anything of much significance anymore. It is just knitting things very basic like knit and pearl stuff, that is all I've been doing. I have done embroidery stuff.
Cooking comes under my hobby.
Acting…definitely not.

Chorale…definitely not. Dancing…I
have an interest in it Comedy…I am
not a comedian.

As Emma read the Creativity Cue, she did not seem overly confident in her creative self. However, as she listed her "hobbies," she began to think more about what her abilities were and what she would like to try.

4.10.3 Initial Read-Through for Narrative Meanings

Emma finds strength when she can encourage her mother's independence. She has found herself coping with dementia through her sense of humour, but she also has much patience. She mentioned that the medical changes were among the scariest and that those transitions took much strength. Emma has a unique perspective in that she balances the difficult emotions brought on by caregiving with her optimism in the situation. Emma stated that dementia does not affect everyone in the same way, which makes her stronger and the other caregivers' strengths that much more significant.

4.10.4 Emma's Creative Project: "Shared Times"

Emma's idea for her creative project involved play dough. She saw herself doing something playful with her mother. She decided to plan a visit where they would make figures out of play dough, just as they used to make cookies, and allow them to dry on a baking sheet. The figures are not all recognizable, and yet they represent a familiarity that Emma and her mother have with each other. There does not always need to be memory, but the memory-making can still exist.

4.11 Luke

Luke on creativity:

A creative person takes all their experiences and what they have learned and what they know and who they are, and applies some combination of those things to a given issue or problem or situation or to help someone or to better deal with someone.

All our lives dad taught me to play guitar; dad and mom used to have house parties virtually every weekend, and we had a lot of friends and family who would come. They were always great times what dad used to call "good, clean fun." A few drinks, but good, clean fun. There was never, again, a cross word between them, never any upsets – all laughter and conversation and music. My sisters and I went to bed as children, many of those nights listening to dad playing his guitar and everybody laughing and singing along with him. Small wonder that I became an entertainer and singer and guitar player.

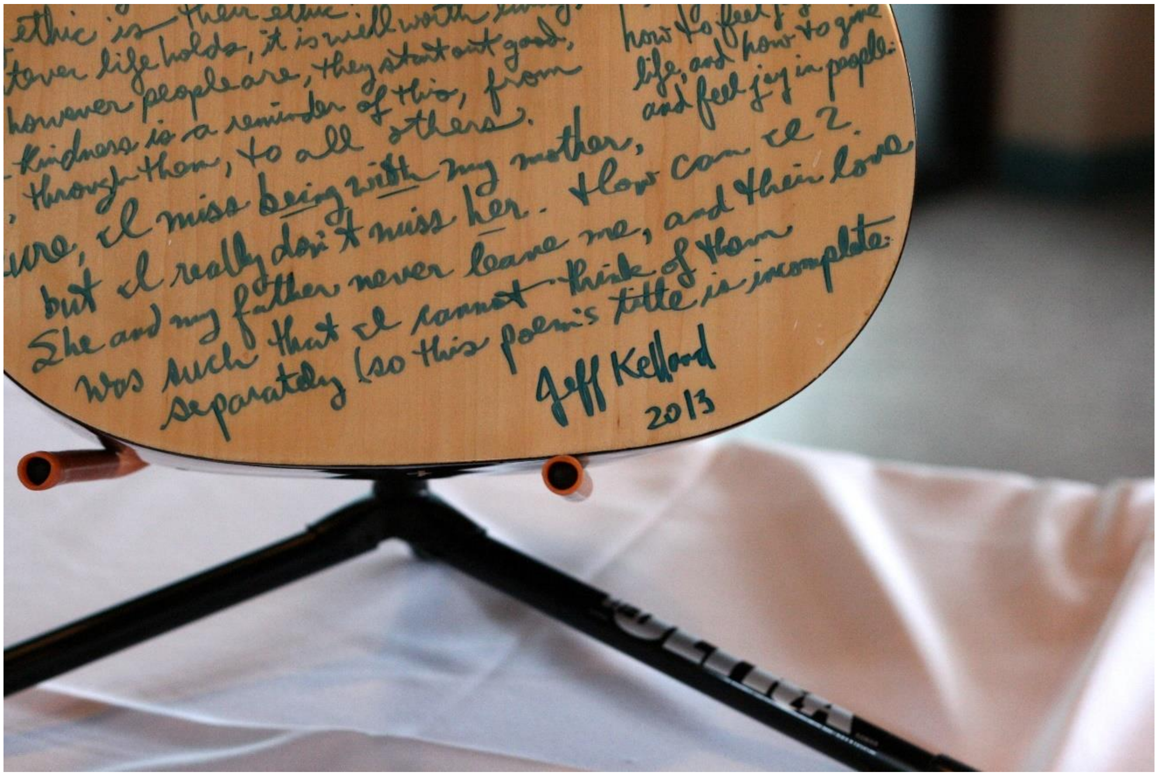


Plate 12 Luke's poem written on an old guitar.

4.11.1 Meeting Luke

Luke cared for his mother, who had passed away a few years earlier. Luke and I met for our interview in a boardroom near his work. Bare walls and a large table with many chairs created the atmosphere. Even though the room was empty, I imagined the sound of the music within his stories. Luke's contribution in the interview felt more like a whole story with a beginning, middle, and end, rather than individual stories in response to individual questions. He told me of his childhood and his parent's relationship. Luke's mom and dad were madly in love, and he stressed how important it was that they were always a unit. Music was a significant part of their daily home life and consequently, one of his most prominent memories of growing up. He cared for his mother after his father passed away and he wrote and delivered both of his parents' eulogies. Luke's theory was that although she had dementia, his mother died because the love of her life had passed away.

4.11.2 Luke's Creativity Inventory

I think the future will have to hold more creativity in the realm of science, and a little less calculation and a little more contemplation.

Writing is right at the top of the list. I used to write a lot of them myself; write a poem for someone and put it in the card.

Guitar is right at the top

Painting: interest. I see myself doing that at the cottage in later years. Something I have always wanted to get around to. I have always been a good drawer but never got the chance.

Acting, yeah, I have done that. I have been in a lot of short films.

For Luke, creativity is a part of everyone, and artists are the ones who practice it the most. Luke writes poetry and music and plays the guitar. While using the Creativity Cue, he stopped on the word “building” and expanded its definition. I found his words to be very powerful:

> *Building…in the broadest sense of the…not just in the carpentry sense. Building on strengths and building on experience, and stuff like that and building people’s confidence.*

4.11.3 Initial Read-Through for Narrative Meanings

> *Bringing together two things that previously had never been perceived to have any relation to one another. It is like that. It is bringing together things to make a brand-new thing, whether it be a thing, or a method of coping, or a way of helping, or dealing with your life.*

> *Trying to maintain as many normal or usual activities that she enjoyed and that she did. Communication with touch, with holding hands and hugging, and proximity, that kind of thing.*

> *Some of the ways when I was with her was to relate with her like I used to, humour.*

One of Luke’s many strengths was his ability to find the positive in his caregiving experience. While Luke was telling stories of his family, he spoke of their loving relationships. Luke stressed the importance of trying to bring joy to the situation. He found it helpful to take time for himself away from everything. He said, “I would go for a retreat for a weekend occasionally, just, like I say, I would reduce my number of obligations, so I could concentrate or even wallow in it. Whatever works. It did not always work, but I tried to make it work” The story Luke told me about his mother demonstrated his attention to expression and communication of feelings. The following quotation shows how their relationship remained intact in whatever ways it could, as the disease progressed:

> *As it moved on, it became more about feeling than about doing. Facial expressions in a certain way and winking that you did not realize that you did before, but now they are so significant that you came to realize that they were actual things; they were real events, just a special kind of wink, or way you put your mouth when you did it. Any way that it communicated or participated in activities that she had always enjoyed.*

Luke used his creativity to communicate with his mother. In this research, Luke represents the strength of being confident and aware of one's creative self, both as a caregiver and artist. Sharing in his mother's laughter was comforting to both of them.

> *…with mom, it was like, you would say a phrase that was sort of an in-joke between her and I. She would laugh, just knee-jerk kind of a response, without necessarily even knowing why; it was almost like something inside of her knew that this is funny for me. I am supposed to laugh at this. She did not have to force it. It was triggered on something other than a conscious or remembered level. It was more a part of her spirit that I had tickled with those phrases*. (Luke)

4.11.4 Luke's Creative Project: A Legacy of Love, Laughter and Live Music

Luke told me that he did not have a lot of time to dedicate to a creative project, but that he would like to write something. He decided that he would articulate his story in the form of poetry. I asked if I could contribute a donated guitar as a medium for his project, and he agreed. Luke had his poem written directly on the surface of the guitar as a symbol of his permanent relationship with the legacy of music in his family.

The previous pages highlight some of the examples of how caregivers demonstrate great strength in their role and how they define and perform their creativity. The interviews provide a chance for the reader to understand and empathize with caregivers through their narratives. The Creativity Cue shows how these caregivers think about creativity and their involvement in creative activities. The Cues give an insight into the areas of caregiving that require creativity and what each participant has to offer. The ideas for the creative project give one a starting point from which to enter the exhibit.

Chapter 5

The Exhibit: “Care-full Pieces of Creativity”

5.1 Introduction

In the exhibit, the individual caregivers and their stories sit alongside each other in the same room for the first time. This chapter presents the caregivers and their stories as artists and artistry. It is not just a space to come to know the artists and their stories, but also a site of “aesthetic contemplation”. Cole and McIntyre (2004) provide a similar written account of their exhibit. They explain “[C]ontemplation occurs over time and involves the evolution of meanings as our feelings and intellect mull over perception” (Cole & McIntyre, 2004, p. 2). As a reader/attendee of this exhibit consider that “[T]he reader takes in what is presented but also acknowledge[s] a place for her/himself” and that “viewers bring their own history to the work and project themselves into it but at the same time experience what is presented” (Cole & McIntyre, 2004, p. 2).

5.2 First Glance at the Room

The exhibit took place in a building nestled in nature with large trees surrounding the outside walkway. There is a long wooden walkway into the building and surrounding the outside. The room is full of windows allowing for plenty of spring light. I arranged the tables along the edges of the room and draped each with white linen. There is a fire burning underneath a mantel accompanied by a stunning brick chimney. The room is warm and inviting. A projection screenplays a slideshow of the artists’ photographs. I removed all artwork or signage in the room to dedicate the entire space to the exhibit pieces. Upon each table is a card with the title of the piece, the artist’s name and the medium used. Next to the title card is the creative project as well as an artist statement. I placed a lit tea light candle on the tables where the person living with dementia had passed away. I did this to honour that person but also to give unknowing individuals an indicator so they may choose to use another level of sensitivity when talking to the caregiver. There is also a journal beside each project and a pen for visitors to leave feedback for the artist. I intend this chapter as a journey through the exhibit.

5.3 Walking Through the Exhibit

At the entrance table, I placed programs (see Appendix E), a vase of flowers, gardening gloves, a bowl of wildflower seeds and a planter. The seeds were meant to be symbolic of the seeds these projects hold.

Plate 13   Opening the exhibit.

5.4 “A Legacy of Love, Laughter and Live Music”

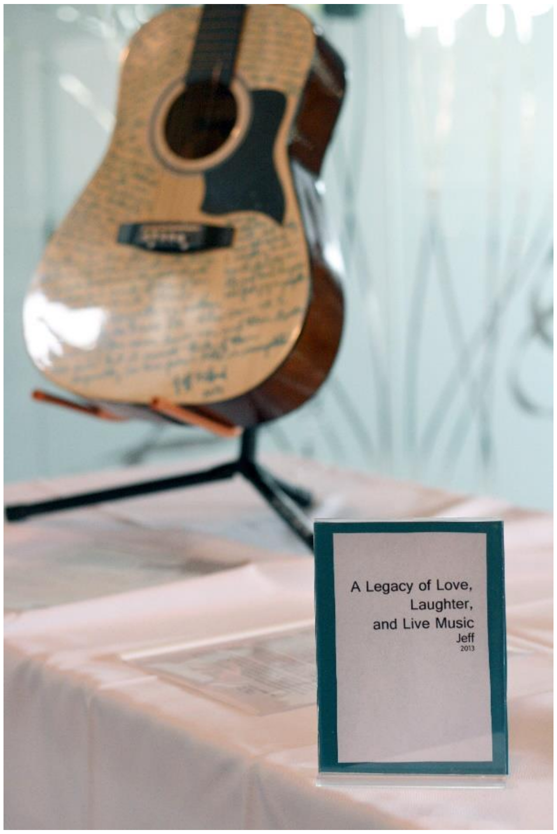


Plate 14 Luke's title card and creative project.

The second table, Luke’s table, holds an acoustic guitar upright in a metal stand. Hand-written on the guitar itself is Luke’s poem. His artist statement is also on the table.

How Can I Miss Her?
Luke (2013)

Sure, I miss being with my
mother, but I really don’t miss
her. How can I?
She and my father never leave me, and their love was such
that I cannot think of them separately (so this poem’s title is
incomplete).

How can you miss someone who is always there
every time you laugh, every time you
dance, every time you sing, and every time
you do someone a kindness?

Plate 15   *A caregiver reads Luke's statement.*

My mother and
father; both have left
this earth,
but they have left
behind everything to
us – how to feel joy
in life, and how to
give and feel joy in
people.

For this is their
legacy of parental
love: a childhood of laughter, music and goodness, giving us an adulthood of laughter,
music and goodness. This was their way, and this is, and shall always be, our way.

My ethic is their ethic:
Whatever life holds, it is well worth living;
And however people are, they start out good,
And kindness is a reminder of this, From us,
through them, to all the others.

Sure, I miss being with my
mother, but I really don't miss
her. How can I?
She and my father never leave me,
and their love was such that I cannot think of them separately
(so this poem's title is incomplete)

Luke's Artist Statement

My two younger sisters and I were three of the most fortunate people we know when it comes to the parents we had, and the upbringing we were given. It was true while we were growing up, when each of us became parents ourselves, during the processes of our parents' deaths, and in our lives since without them.

As the poem illustrates, as children we grew up in a household full of love, laughter and music – essentially, caring wrapped in creativity. Both parents were always ready to laugh and tell a joke, always in good taste; they played good music around the house all the time, often used the lyrics to teach us one lesson or other, and there were countless *weekend house parties of guitars, singing and good clean fun. We were indeed fortunate; and our children, in turn, experienced very similar upbringings, with plenty of music, laughter and, until recently, Mom and Dad. There is no joy in seeing a parent through a long and painful, multiple-year process of dying, and it was difficult for us to have to endure this experience with both parents, with just a couple of years between our father's passing and the onset of our mother's illness. Even so, the creative caring given us over the years years, and the daily lesson in love and parenting it taught us, prepared us for when the time came for us to "parent" them. It came naturally to us, and it was a comfortable "place" for us all to go to communicate caring and love, during their final ordeal. And now, pushing forward without them, it is still laughter and music that sustains us, triggers innumerable fond memories, and comforts us when we need to be reminded of the gift our parents' caring and love was, of just how fortunate we were, and how their love and caring was delivered on the sweet wings of creativity.*

Plate 16 A community member at Luke's table.

My hope for how my poem can help someone else? To let people presently in the midst of their pain know that bad memories, like those associated with the slow process of dying, will fade into the background more and more as the years go by, you will find that the good memories will shine through more and more, and in time they will be all you remember. Take heart, and take care of each other. Luke, May 2013

5.5 Continuing through the exhibit

A husband looking up at the image projected on the screen at the back of the room. This is Jack's wife. He stands there looking on and, even though you cannot see his face, you feel the emotion. He has never turned his back on her. I love that the photographer who (had no idea who was in the photo) captured this moment. This image draws up so much emotion every time I come back to it.

Plate 17 Jack looks at a projected image of his wife.

5.6 “As the Curtain Closes”

On this table is a framed canvas displayed on a wooden easel. Ren made the canvas into a window. Curtains are hanging off a wooden dowel curtain rod. On the window, an empty embroidered crossword puzzle and beside it, the clues for “down” and “across”. Beneath the curtains, stitched underneath are two columns, which exist as a poetic representation of two perspectives. One column represents the artist’s perspective as a woman caring for her husband, peering through the window of dementia, and the other perspective is that of her husband.

Plate 18 Ren's framed window with embroidered crossword and title card.

Ren’s Artist Statement

My creative piece was suggested by Megan. It was perfect for me because I always liked doing embroidery for relaxation. As my husband liked doing crossword puzzles, later…word search and then just happy to sit and watch me.

Caring for someone with dementia is like the frustration of doing a crossword puzzle where all the clues are jumbles and don't fit the usual pattern.

I started with a white canvas art board 11 x 14. I then drew a crossword puzzle on a piece of paper. I chose a piece of white cloth and copied the puzzle with words and numbers. White cloth because I wanted the colors to stand out. For the words I used bright colored threads. Bright colours enlightened me because I like nature and outdoors, sunshine, flowers, smells and sounds of nature.

They make me happy, relieve the stress and gives me strength. With coloured threads I embroidered words for my puzzle:

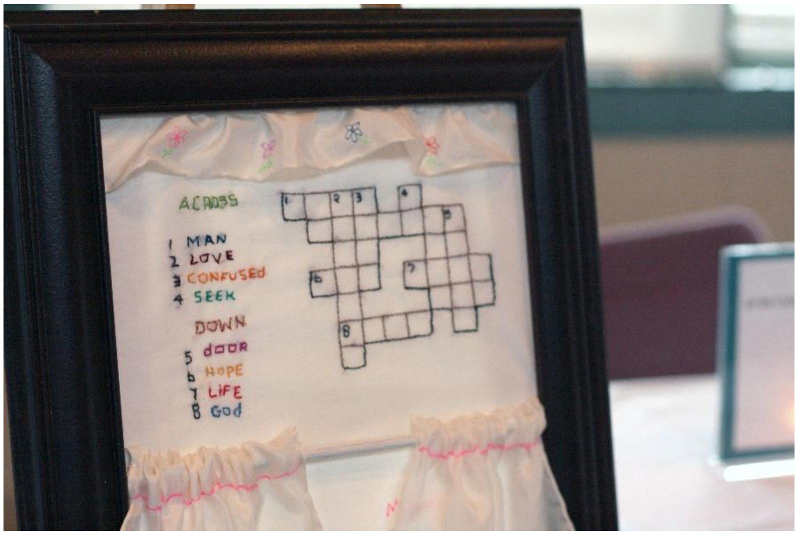


Plate 19 Close up of embroidered crossword clues.

Man	*He was a caring, wise and gentle man, who loved his family.*
Love	*Because there was a bond of love between us.*
Confused	*Describes how we both felt living with this disease.*
Seek	*Always a need to try and find what was lost.*
Door	*Means my door to his life will always be open.*

Hope	*My hope was that I would be able to care for him without intervention.*
Life	*The life I had with him was slowly slipping away – I became his lifeline.*
God	*He had faith in God but the more he lost his understanding of God, the more I trusted in God to get me through.*

I used coloured pencils to make my poems. Curtains from a see-through white silk scarf. I first cut the topper and painted some bright colored flowers. I stitched it to make it gathered and then cut, stitched the bottom curtains, and painted flowers as well. I found a frame that was perfect for this window. It looks like a window frame. With glue stick, I attached cloth to canvas board. Then secured it in place in the frame. With glue gun, I added extra glue to keep it in place. I painted a wooden dowel for a curtain rod. I cut and fitted it in the window. The top half of the window is the embroidered crossword puzzle. At the bottom of the window under the curtains are my poems.

Plate 20   Peeking under the curtain.

Finished Product material: *Embroidery threads, white silk, pencils, glue, frame, wooden dowel, canvas, paint.*

Creating the window for the most part was fun and rewarding. The part that was the most difficult was recalling what I have lost through this terrible disease. Maybe I will realize later that it was therapy for me ?

My journey is long and difficult. It started when my husband had just retired from 30 years of working in a mining town. I was looking forward to travelling… and doing fun stuff together. But then he started to show signs of dementia and because of his family history of Alzheimer's we consulted with the family doctor who tested him and started him on Aricept which the Doctor explained it helps better if started in the early stages of Alzheimer's. He explained it would help slow the progression but was not a cure. It really did slow it down. The doctor was always pleased when he saw him about every six months. He would only lose a point on the test.

It all started when we could not relate to each other. He was okay with getting checked out and going on Aricept. I noticed that when we would go to the doctor for his pills, I guess while we would be waiting, he would get a bit anxious knowing the doctor may do the memory test on him. And he would do poorly on the test but once I clued into that I would talk to him and look at books, anything to keep his mind off that and he would do much better. It was easy to take his mind off something by distraction in a calming way.

He did very good in the first few years, even though his behavior was changing every day. I could see it, in all the little things he could or could not do. He was great at fixing things like small appliances. But then there were times when he took something apart and put it back backwards, or just could not get it together at all. I would watch him and label things so I knew when it went together it would be okay. And he felt relaxed with that and didn't get uptight. If we bought something that had to be put together I would read and guide him. I learned a lot by that and I learned a lot from him over the years. He was very intelligent and could figure things out quite quickly. He was general foreman at a mining company and did his job well.

I always like to paint the walls of my house and he would do the trim. Then over time he would only half do it. He was always a very good driver and we travelled everywhere. He did all the driving and never complained. That started to change, where I would have to say right or left, then to pointing my finger right and left because I realized he did not know right and left. Then the lights I would have say stop on red etc. Until finally I was doing most of the driving and when he had to get the driver's exam, the doctor would not sign it. Even though he did not drive, in his mind he thought he did. He would say: do you want me to drive you there? But he would go out and sit in the passenger seat, or he would say, "Did I lock up my car when I came back?" And he always would put the keys in his pocket. If he saw a set of keys lying around, he would take them…that went on forever. So I had to find a hiding place for keys because I was afraid that if I went out he would go in the car. When he was driving, he would sometimes go a short distance for gas or up the road for cigs when he smoked and would be gone so long because he got lost. It was nerve racking.

I had to do many things to help cope with his every day changes. I put the pictures of our five children on the wall in front of the bed so he would not forget them. I found I could not tell him beforehand that we were going somewhere or he would get anxious about that. All through the night he would be poking at me to see if I was in bed. He did not sleep well if he heard me say I was going somewhere the next day. I would have to wait until it was nearly time to go or just enough time to get ready.

As he progressed in his disease he would keep me awake some nights, checking to see if I was in bed. I finally had to get a sleeping pill for him so we could both get some rest. He would wake up during the night and say his mother just went out there and he would get up to look for her, sometimes his mother and sister. I would tell him his mother is in bed asleep and that use to satisfy him. He would go back to sleep.

Sometimes he would go out to the living room calling out to me. He would say I thought you got up, I was looking for you. I was afraid he was going to fall over the stairs so I used to put a stool across the door to the basement…But sometimes I would be so tired I would hear him but not notice he would put his shirt on his feet and I would find his slippers in the bed.

Sometimes I would be so frustrated but never once did I say anything negative to him. I would always talk calmly to him so as not to stress him. I knew he could not help it. He was such a good husband and father and he would support me in anything I would do. I would get through it by going for my exercise like running or swimming. In later years he would always want to go with me, but if I said I was going swimming he would be okay to stay home. But anywhere else I went I would take him along.

He was happy as long as he could see me. He did not want me out of his sight. He would not stay in his chair or doze off, he had to follow me all around the house. The only time he would stay in his chair was if I was sitting by him. When I couldn't leave him alone I would have homecare for four hours 2 or 3 times a week. I looked forward to that. I could go for a swim or skate. That was my stress reliever. Then I would be able to cope with anything another couple of days. I think anyone in this situation should have time for themselves for sure. It's the only way to cope.

We always enjoyed playing cards and playing darts. He was so good with numbers. Darts and cribbage, he only had to glance and he had it. It got so he didn't want to play darts. It was like a chore and with cards he forgot the numbers. He did not know a 5 from a 10. That use to make me sad. I think the first time he asked me who owns this house, I was heart-sick over that. Things that would make me laugh was out of the blue, he would say something witty, or answer a question as if there was nothing wrong and the next minute he would not know what I was talking about. He was so fast on doing crossword puzzles and finally he couldn't do them anymore so I would do them, from the newspaper and sometimes I would ask what's a four letter word? for something I had not heard of, and he instantly would give me the answer. I would be shocked, he would not be able to explain anything, and he was very quiet and didn't talk much. If we went to our friends or his brother's house he didn't want to stay long. He would be very tired after supper and wanted me to go to bed. He would not go to bed alone. Even playing cards he would seem exhausted after a couple of games. It seemed like any time he had to think about anything, it was hard work. So maybe not thinking or wondering was easier. I wish I knew.

When I reflect on my caregiver journey, I thank God I was strong enough to take care of him and stay sane, because living with someone with dementia is not an easy journey. I would do anything to have him back – I miss him so much – I grieve a lot but sometimes I have to say maybe… instead of being angry with god. I think that maybe he was kind to me. As the Alzheimer's stole him from me long before that. I think of him as in a better right.

5.7 “I am my hat”

Plate 21   Amelia's felted wool hats.

Beside the next table there is a hat rack with three coloured, felted wool hats. The hats are very different from each other. They each have a tag. There is a green hat. It is the largest of the three. The tag reads “camouflage”. Below it, is a navy coloured hat with a pink felted flower attached. The tag reads “determined”. The third and smallest of the hats is bright red, also with a felted flower. It holds a tag that reads “Good day”.

Amelia’s Artist Statement

Materials: *pure wool. Sheep’s wool or Alpaca. Some have a mixture of Mohair. The flowers are also made with felted wool.*

Red Hat “Good Day”
Here is me on a good day. When things are going right in your life, you’re a red hat person.

Navy Hat “Determined”
Steadfastness. Determination.

Green Hat “Camouflage” *I’m not feeling good. I’m not feeling confident. I’m showing, “I am somebody”.*

Plate 22 Amelia at a craft fair with her hats.

I’m now an 80-year-old woman looking back on my life. Mostly I see a lot of happy times. The birth of my children, their marriages, their troubles and successes. In reflection I also see a lot of work, a lot of laughter, pain, anxiety and resolution. When I wear a hat, I *am as good as anyone. I’m me and I am proud of me. Me, or any woman in a hat, I feel it is an added bonus to her. I’ve had people say to me, “I see your hat coming before I see you”. You put on a brave face with a hat. I will assert myself. I’ve worn a hat quite a bit this winter. It puts on a brave face. Hats are more than a brassier. They saved my life in lots of ways. With Alzheimer’s there is no good going to reality. Try to erase some of the mystery they are feeling. Sometimes you get so frustrated. Wearing and making hats and giving away hats, it’s like a cycle where everyone gets excited. It’s a diversion. The first hat I ever gave away was to someone who wasn’t as outgoing as me. She pranced around in her hat. It’s not a place of hiding but it covers the insecurities. Hats gave me a license to do something just for myself. This project gave me the impetus to think differently about hats. She becomes the hats she wears.*

5.8 “Full Circle”

This table has multiple items to look at. There is a painting with rustic colours depicting an older woman sitting at a restaurant table. There is a poem Linus has handwritten on a page torn from a journal.

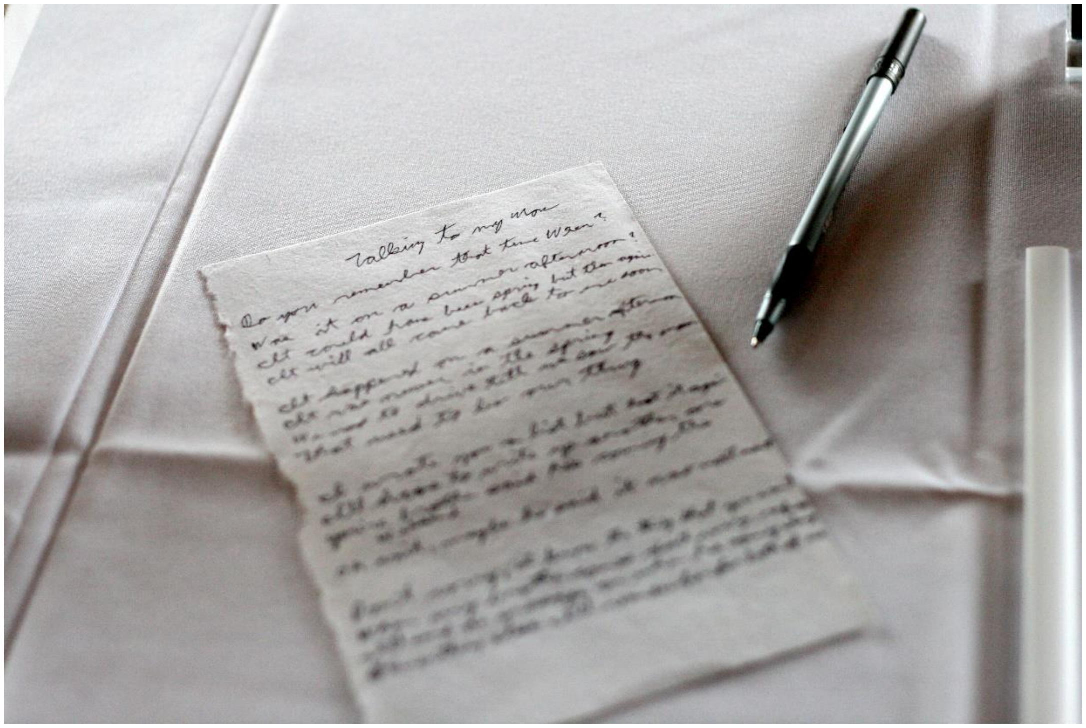


Plate 23 Linus' poem written on a torn journal page.

“Talking to my Mom.”

Do you remember that time when?
Was it on a summer afternoon?
It could have been spring, but then again It will
all come back to me soon.

It happened on a summer afternoon It
was never in the spring.
We used to drive till we saw the moon.
That used to be our thing.

I wrote you a list but lost it again
I’ll have to write up another one

Your brother said he is coming this weekend Oh
wait, maybe he said it was next month.

Don't worry, I know the thing that you want
When my brother comes. Don't worry, no fuss
I'll send a message when he coming along.
Everything else, I'll remember for both of us.

Near the poem is a short story, and an artist statement. Sitting off to the side on the table is a clown nose and a set of glasses. There is also a long rectangular canvas holding a comic strip illustrating a conversation between Linus and his mother.

Plate 24   Linus' painting and comic sketch.

Comic Strip Dialogue

Hello…Hi Mom…Hey, [Linus] …Nothing, same thing…You're in training? Nothing, same thing…I lost my hearing aid can you speak clearly…Nothing, same thing!! Oh, you're BBQing?…No, Nothing. Same thing…Have I told you my sisters are taking me around the bay?...Oh…that's great…How did you know we're leaving at eight?...I didn't. I said that's great….You didn't say that's great?...Did I mention I lost my hearing

aid?...Yes you told me that!...Tomorrow I should take a hat?...I don't know anymore…What am I doing tomorrow?
Did I tell you my sisters are taking me around the bay? Hello?...Hello!...Huh… must be a wrong Number
(click)

Linus' Artist Statement

Hi, my name is [Linus]. My first love is the stage, but my second interest is paying the bills so my first love has to wait. I also enjoy writing and painting.
My mom has Alzheimer's and to be honest it's scary. Waiting for that inevitable day where I find her looking out the window with blank expression on her face is heartbreaking. If you don't have a sense of humour, you're not going to make it. That's what its all about really, a sense of humour. Every day is like an Abbott and Costello "Who's on First" schtick. Sometimes I have to lie to her; other times, I have to distract her. Then there are times where the train is just heading down that track, and you have to grin and bear it. But she's my mom, and it would be so tiring if it was someone else and I can't help but think of the cycle of life thing playing itself out here. So I enjoy her as much as I can when I can and be patient and deal with any grief later.

So I come across Megan and thought this would be the perfect way to express myself and my love of my mom. The painting is me and her (though I'm not in the picture, because it's me looking at her) at Bamboo restaurant. As you can see, I made Bamboo restaurant pretty empty, and obviously I took liberties with the layout. I just wanted to focus in on her, and the rest is just tapestry. The poem is what mom was best at, poetry. So I wrote the poem in honour of her and what she did so well. The comic strip was for me, actually. It's a nod to my sense of humour and is so crucial in this time in my life. The short story is what I love doing. That is, writing narrative. It portrays a single moment of an afternoon with mom. It sums up everything about me and mom and how we get along with each other. I just want people to know that, yes, it is scary but it's also strangely rewarding. You'll be surprised at just how strong you can be and how you'll get a bond with your loved one you never knew you had. Not that you never had a bond with your *loved one before, just a different evolved bond. And I hope that after all is said and done we're all stronger for it.*

Linus Reads His Story Aloud

Mom's Day

He finally got to mom's room at the Manor. He opened the door, and there she was working on a word finder book as usual, tv ignored in the corner blasting away. He put away the regular goodies she wanted, went up to her and abruptly put his face up close to hers.

Plate 25 Linus reading his short story.

"Hey ma! Hahaha."

"Oh YOU! You want give your aging mother a heart-attack!?" mocking anger. "I got your stuff." "What about the important stuff?" she grinned. "6 big ol' bars of chocolate. Right next to you." She looked over and was surprised, "How'd they get there?" "No wai..."

She turned back to him, "I just cleaned this place and no matter how much I try to organize, this happens."

He quietly scanned the room as she went on, noticing the clutter was the same only it was switched around in yet another ingenious fashion.

"... and I'm missing all my pens. I think someone comes in here and takes my stuff." "No one comes in to take your stuff, mom," he argued, "Who'd want your stuff anyway?" "Well I do have a lot of stuff, they probably think it wouldn't go missing, but it does." she griped. "They probably think they're doing you favour", he quipped, looking at all the mess. "You think they're taking my room

over?" she cried, "Who do you think is doing that?" "No ma, they probably think they're doing you a favour!" talking louder this time, "Are you wearing your hearing aid?" "Why would they want my lemonade? I don't have any of that." she thought it over, "I have gingerale, maybe that's what you heard."

Silence as he controlled his laughter. Then he went over to where she usually kept her hearing aid and held it close in front of her. Mom just looked at it for a while, entranced. Finally, beaming like a little girl, "Ohhh, you meant hearing aid." She took a moment to put it on. "Now what was I talking about?"

This time he stood there entranced trying to remember what they were talking about it. For one brief moment he wondered if dementia was contagious.

"So, what's new, ma?"

"Oh, the sisters came over to visit me on the weekend. Peg put in a new battery in my hearing aid after she found it again."

"Mom, you have to stop throwing the hearing aid after you get fed up with it. Phone me and I'll come over and fix it."

"But I don't want you to come over from all that way."

"What do you mean? I don't live that far away."

"Don't you live on Posser's Rock now?"

He stopped at that. This was new. How was he supposed to approach this one?

"Ma I live off LeMarchant Road; there is no Posser's Rock."

"But someone told me your work moved to Posser's Rock. Didn't they move the prison there?

"What? The prison didn't move anywhere, and I'm not living on Posser's Rock. There's no such thing as Posser's Rock."

"There's no Posser's Rock?"

"Well, there probably is a Posser's Rock. Oh crap!" he realized.

"So, there is a Posser's Rock." she said smiling like a little girl who won an argument.

“Yes, there may be a Posser’s Rock but not with me or my workplace on it.” he said, wearily. “Look, I’ll write my address and my work and phone number on a piece of paper and put it on the fridge door.”

“Oh goody, that’s a great idea.” she smiled.

He spent a half an hour to find a piece of paper and a box chuck full of pens tucked away in a corner along with a year old royalty check and two drivers licenses. He couldn’t help but admire her ability to hide things so well in such a small place without even intending to.

“Okay, it’s done.” as he exhaustedly stuck the paper on the small fridge with a fridge magnet conveniently found along the way. It read "Please be Patient, God isn’t Finished With Me". How apt he thought.

He remembered being five, sitting on the big couch in the living room, a stack of children’s books beside him. Kindergarten was over and it would be hours before she’d get home. Dad was downstairs being a barber. He liked to play this game where he’d the books, and with each word he’d see he could hear mom’s voice saying the word. It got sometimes to the point where it seemed like mom was right there reading the words to him. It turned out it came to be the way he learned to read. By the time he was eight he was able to read whole articles from newspapers. It became an endless source of entertainment with the adults. Dad and other relatives would show his talent off in corner stores. They’d pluck a random magazine and get him to read any old article they’d pick. One day they got him to read some article, when he realized there was a ruckus elsewhere. He finally looked up thinking the ruckus was about him, but it was his brother had gotten lost in the store and was crying. Dad and some relatives were laughing at how cute that was. He realized how easy it was to distract the adults. He never read articles for their amusement after that.

“I was wondering if you could get my computer going again. I’ve been itching to play scrabble.”

He went to the laptop. He was baffled by the fact that this little thing could browse the internet while using Microsoft Word and play scrabble all at the same time. But no, she just wanted to play scrabble on it. He admired how she was in no way scared of technology; instead she kept coming at it like a cat coming at prey that was a little too clever for it. So he got it up and running and spent another half an hour writing notes for her and showing her how to get on scrabble. Then he spent another half an hour writing notes for how she can use the internet. Each time he came and showed her she had access to the internet she was genuinely surprised all over again. And when he'd come and visit her again he'd do the same thing all over again.

“Have you been keeping in touch with the writer's guild?” He asked.

“Yeah, in a way. Bernice calls from time to time.” she said, quietly.

He stood looking at large amount of books he knew mom would never get to read. "You want to play crazy eights? We'll go to 100.”

“Yes, that's what I like to hear.” she smiled gleefully.

He spent another ten minutes to find the deck of cards. He handed mom a box of crackers to keep her occupied. It was like taking care of a daughter. Shuffling the cards he laid them face down and cut from the top. He turned it over revealing eight of clubs. “Okay ma, cut the cards.” She scoops up the rest of them and reveals the very bottom one. King of diamonds. “I win!” then giggles foolishly. That's one way to do it, he thought, then handed over the cards to her. She shuffles and deals out three each, picks up her cards to look at them.

“Where's the rest of them mom?”

“Rest of what?”

she looks up above her cards, one eyebrow cocked up quizzically.

“Were supposed to have eight cards each for crazy eights.”

She thinks a moment then her eyes light up, “Oh yes! So we were too.” Then she just laughs and reshuffles the cards and doles out eight each.

He never said a word but just reached over and revealed a card from the top of the deck and put it down next to it.

"Oh right, I keep forgetting that." she says, still focused on her hand. He had just had to laugh at that.

"What's so funny?" she asked, incredulously.

Still laughing, "I keep forgetting that."

"Keep forgetting what?" she asks completely innocent. He laughs even more.

"You forgot you were playing Crazy Eight," he says through laughter, "but you remember that you keep forgetting to reveal the top card when you do play."

"Oh!! You know you shouldn't be laughing at your mother." slapping him on the shoulder.

Silence passes as they play Eights, marked by passing of the cracker box back and forth between them.

"You know your Aunt Marge is in the hospital?"

"Yeah, I've known the past week." He said, disappointed as she was the only one of them he wanted calling him about his mom's developments. He thought how unexpected it would be if Aunt Marge died before his mom. He never even bothered to ask what was wrong with her or even why it was the doctor's fault that she ended back in there again. Was it because at their age you're just waiting for them to die? He wondered if he was the only one who felt that.

"Last card." he said mockingly, tapping the card on the bed.

"Oh, curses!" she thought hard about to play several different cards then changing her mind then finally laid. Six of hearts, he smiled and laid a six of diamonds on top of that.

"You're up to 100, I win ma."

"You want to play another?" she asked, hopefully.

"No, I know better than to play you for too long."

The nurse came in to give mom her pills. He listened as she talked to mom as if she were mentally disabled or something. Then again, he realized, she was mentally disabled. He waited patiently as she clued up and refrained from not saying something snide or off-handed. Finally she finished the small talk with mom and left the room.

"I really wished they served good food here." Mom said abruptly, "Everything they serve is either mushy or rubbery and bland."

"That's what these homes are about, ma. Cutting corners to make a buck." he said.

"Oh yes, could you help me find my purse? I need some money so I can pay off the hairdresser."

With that another half hour was spent on the quest for her purse. He managed to find it, deep in a little shelf on the tv stand. He looked inside and to his relief was $40.

"I have the money here." he called out to her, "I'm going to put this right here where you can see it on the nightstand."

"But someone will take it!" she exclaimed. "I have to put it somewhere."

"Mom, look, if you put it somewhere then you can't find it later. You always end up thinking someone came in and took it." He put the money on the dresser and purposefully put a cup on top of the bills. "Believe me, no one will come in and take your money. Unless it's you, paying your hairdresser." She smiled mischievously at him, "Okay, okay. I'll keep it there, sweetheart."

He had the feeling that he scolded a six year old who only pretended to go along with him and get in trouble as soon as his back was turned.

"I wish I had a dog here." she said.

"You do?" he replied, wondering where this was headed.

"Ever since I met those two cute things your friend used to bring over, I thought they'd be pretty good company."

"Even a small dog would take you off your feet if you tried to walk one." he laughed.

“What if I got a Newfoundland dog, I could hitch him little wagon and he could tow me around town” she said with that silly grin. The thought of this made him laugh so much.

“I’ll tell you what, I’ll get you one of those robot dogs.”

Her eyes lit up, “What a great idea.”

“What’s a great idea?” he said with a smile.

Mom looked confused for a moment, “I don’t know, what’s a great idea.”

He couldn’t help it; he just lost it laughing at that. It’s not that he was doing it to be mean, he just did it so that there was some kind of humour involved. After he calmed down a bit he told her, “The robot dog is a great idea. I was just messing with you.”

“Oh! I’m going to hit you with my cane.” she said. “They won’t let me go out on my own. It’s not fair. One of these days, when they’re not looking, I’m going to get into a cab and go somewhere just for the hell of it.”

“You know you can’t do that.” he replied, “Besides, you wouldn’t remember where you wanted to go and how to come back. What if you went to a place where there’s no phone?

“I know how to take care of myself.” she quipped, “I’ve been doing so since way before you were born.”

He stood there wondering what he could do to distract her from this head of steam she was building. Looking around the room he noticed the chocolates. “Hey mom, have a bit of Cadbury Almond bar.”

“Oh! Yes! Just the thing.” she opened the wrapping almost ritually and broke off a couple of pieces and delicately savoured it. He never saw someone enjoy chocolate quite like his mom. Crisis averted.

Looking around the room, he saw the all the books strewn everywhere. All the knick-knacks thrown here and there. There wasn’t much difference in the way she lived her life now compared to how she lived before she... well, forgot everything. He resigned himself to keep forever teaching her how to use the computer. Sometimes he’ll try to remind her of the things she’s done in the past, but it won’t work quite the way he thinks *it will. She's done things in her life, achieved so much, but it doesn't really matter now, she just enjoys her chocolate and some shows on tv. She'll complain about the food, how it's so bland and how the home just cuts corners. Once, a while ago, it seemed like she remembered how she used to fight for the old and disabled. She thought that all the staff was trying to swindle the people living there. She was adamant about it and told him she is going to take it to NTV to expose the whole thing. He never saw her so mad, even slapping him on the shoulder like some kind of brother in arms. A couple of weeks and additions to the medication later, she's like a little girl that he's now come to know.*

"It's just about 5pm, ma," he said.

"I don't want to go to supper." she replied with an exaggerated grimace on her face. "Their stuff is so bland, or it's bland and mushy. It's like no one here ever got cooked a decent meal in their lives."

He wondered if people stopped caring what things tasted like after a certain age or if their taste buds just gave up on them. In mom's case he was almost sure it was something for her to latch onto, to gripe over. If it wasn't shoes never ever fitting right it was her artificial leg too tight or too loose or too tight or too loose or too...

I wish Balley Home would get back to me about a vacancy." she exclaimed. "They look like a place that serves good food and really nice scenery outside."

He knew she wouldn't get into that home because he phoned them and took her off the list. What was the point, he moved her once, why go through the stress of moving her again? He went through that with his dad. Last going off he moved him from his apartment to a home around the bay. That didn't work so his dad wanted to try living again in a smaller apartment to see if he could live alone again. That was a disaster so he ended up at an assisted-care home. He was not going through all of that with mom. The next time she moved it would be to a place where she would have full-time care.

"Ma, you know that if you move into Balley Home, you'll find something to pick away at like here." he explained.

"I have someone I know there that said the food was great and they let you go out whenever you want." she explained, "Could you call them again later to see what's on the go?"

He knew that the person would have been allowed to go out because she wasn't suffering from dementia. This person probably lost her taste buds like he suspected with people at old age.

"Yeah, ma, I'll get on it for you."

"Ever since the doctor found there was bacteria in my brain, my memory has been weird", she said, "But it's getting better now, before you know it I can get back to writing checks again."

He cringed. He took over mom's account awhile back when it was clear she was writing multiple checks for the same bill. Whenever he heard her talk about the bacteria on the brain thing, he felt a tingle at the back of his neck. Where she comes up with stuff like that he didn't know. But she had an answer for everything.

"Have you been talking to your brother?" she asked.

This was her way of saying she never heard from him. "My what?" he said, smiling slyly.

"Your what? What do mean your what?" she looked puzzled.

He laughed for a bit, then said, "My brother, no I haven't heard from him."

She faked anger and poked him in the chest, "Why do you torture your own mother like that."

"I don't know," he said smiling. "Easy target?" She laughed at that.

"So, remember your old friend who came in with the dogs?" she enquired. "I wish I could have just a little dog like that."

He darkened a little, then had to smile. "Well, maybe you could get a Newfoundland dog so you could get it to haul you around town in a little wagon." a sly smile creeping across his lips.

She thought about it, at first confused, then her face lit up. "Oh, that would be just the thing!!"

They both laughed together. He just had to enjoy the moment.

Finally they settled down. "I have to go now, ma."

"Okay, I have my things and my scrabble on the computer." she said giving him a hug. "Are you winning at the D & D games?" her arm still holding his shoulder.

He thought to explain there were no winners, "Yup, I'm winning."

"See you later my little sweetheart!" she said, laughing.

"Okay, I'll call you later."

He went to the door, looking back for a second then went on down the hallway. He looked in the main office and asked the worker for his mom's mail. He felt bad to have to do this but she would order all the stuff from the magazines. Damage control. He'd take all the mail back to her later, minus the order forms and the junk. Going to the porch he stopped and went to look in on mom one last time. He saw her there poised over the Scrabble game on the computer, completely engrossed and content. Here was someone who worked on the Christmas Seal going to the coastal communities delivering tuberculosis vaccinations. She worked in rehabilitation for 35 years getting disabled people on their feet. She created a social club for mentally and physically disabled people. Two books were published in her name and countless plays and poems were published in magazines, aired on radio and briefly on a local tv show. She won a lifetime achievement award at the LSPU Hall and, he suspected, a bunch of stuff that she never even bothered to mention. When he was born she won a Pippy Award for disabled people, printed in the newspaper with a picture of her with him as a newborn on her lap. Absolute captain of her own finances. For a brief moment he struggled with all of this and tried to reconcile that with where she is now. He realized it didn't matter; it all happened and that's what's important. He knew it happened and so did a lot of others. As long as he remembered all of this about his mom then it will always be important.

Plate 26   Amelia speaking to the room.

As Linus thanks his audience and leaves the podium, Amelia confidently walks up to microphone and asks to say a few words. Everyone in the room is standing with complete focus, as they were with Linus' presence. Amelia thanks Linus and says that she enjoyed his reading. She makes a statement about how it must be a lot different to be a young person caring for an older person. She expresses that she is an older person caring for an old person, but has always been caring and that she needs to care for herself as well.

Plate 27   Attendees listen attentively to Linus and Amelia.

As she speaks about her experiences of ageing, Tavish’s wife stands in the center of the room bursting with affectionate remarks about holding a baby.

5.9 “Oh Moon”

Plate 28 Rhona's framed images displayed in a window.

In each square of the window, there is an image overlayed by a transparency. Each transparency is entirely black except for the moon, and the images representing things important to Rhona are only visible through the moon’s markings. There are three images: “Oh Danny Boy” piano music, Rhona’s recipe book collection and her recipe for blueberry cheese squares. The fourth square is only the moon transparency. Although

Rhona had to leave my study before she could finish her creative project, she gave me partially transcribed music for "Oh Danny Boy" and a copy of her famous blueberry cheese square recipe.

5. 10 "Things are Changing"

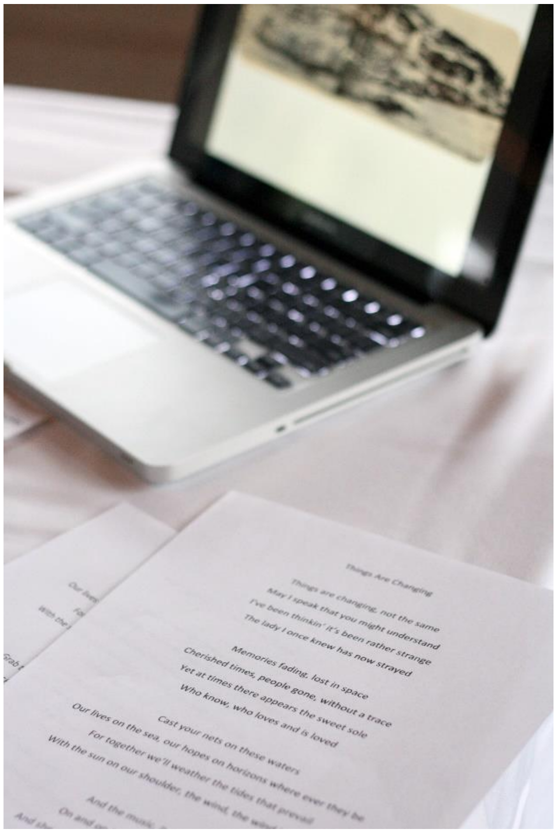


Plate 29 Isobel's listening station with slideshow and lyrics.

On the next table is a laptop and a set of headphones and the lyrics to Isobel's song (printed below).

Things are changing, not the same
May I speak that you might understand I've
been thinking it's been rather strange
The lady I once knew has now strayed

Memories fading, lost in space
Cherished times, people gone, without a trace
Yet at times there appears the sweet sole
Who know, who loves and is loved

Cast your nets on these waters
Our lives on the sea, our hopes on horizons
where ever they be
For together we'll weather the tides that
prevail With the sun on our shoulder, the
wind, the wind in our sail

And the music, it does play
On and on in the room far away
And she naps and she dreams and she sings
And together we cherish these things

Cast your nets on these waters
Our lives on the sea, our hopes on horizons where ever they be
For together we'll weather the tides that prevail

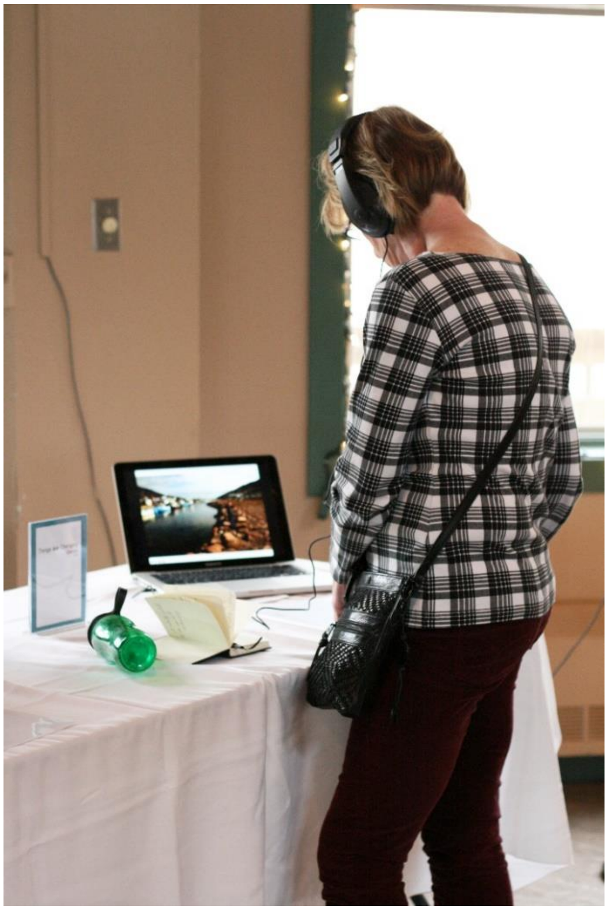


Plate 30 Listening to Isobel's singing.

With the sun on our shoulder, the wind,
the wind in our sail

Another day, set adrift
Shortened visits, and time flying by
Grab the grub, sweep the floor and just
smile
She is safe and at home for awhile

Cast your nets on these waters
Our lives on the sea, our hopes on
horizons where ever they be
For together we'll weather the tides that
prevail
With the sun on our shoulder, the wind, the wind
in our sail.

Isobel's Artist Statement.

My name is Isobel. I am the only child of Howard (88 years) and Sarah (85 years). My mom has an Alzheimer's type dementia that was diagnosed about 5 years ago. She is a bright, determined, well read, intellectual who taught school, raised her siblings, cooked the most delicious meals, cared for ailing relatives, and was the resource historian for her community. In my youth, it was not at all uncommon to answer the phone and have a voice on the other end request that I ask mom "who was Jack's Jacob's wife's sister's child"...and she knew, as well as the birth date and other familial tidbits. That ability to recall and retain history amazed me, and is probably what I miss most. My parents live independently, actually co-dependently... Dad's mind is as sharp as a tack. His body is failing. Mom's body, though much altered in size, is healthy. Her mind, memory, core being – failing. Together they are safe with regular visits from friends and family as well as obligatory check-ins from me. Obligatory - on my part, not *my parents - they are gracious and thankful for any moment I have with them... and when I have time to reflect - I am too.*

I work full time as a nurse practitioner. Have a supportive and loving husband, as well as two girls (age- ten and eight). My doctor describes me as being part of the "sandwich generation"—responsible for and squeezed between two generations. And "squeezed," at times, is an understatement! There are times my work, with science and guidelines as resources, is so much easier. I can solve medical challenges, ease patients and their families' fears, and assist patients to transform smoothly back to their life. When I leave work, the reality of my life smacks me in the face. Head into the wind. I take it on.

When I saw Megan's flyer looking for caregivers of people with dementia, I selfishly thought, I might find some support from being involved. In retrospect, I gained insight into me. This creative project allowed me to dig deep and uncover the "artist" within .... rediscover the poet, the music, the feelings that my life's challenges buried. For this project I have borrowed a tune and some words of a song by Alistair McGillivray. My apologies for the plagiarism and drifting from tune. Music and poetry has always been a part of our life. My mom played organ, I sang. My mom wrote poetry and prose for all occasions. This was the right fit. Adding pictures of our life and home grounded it.

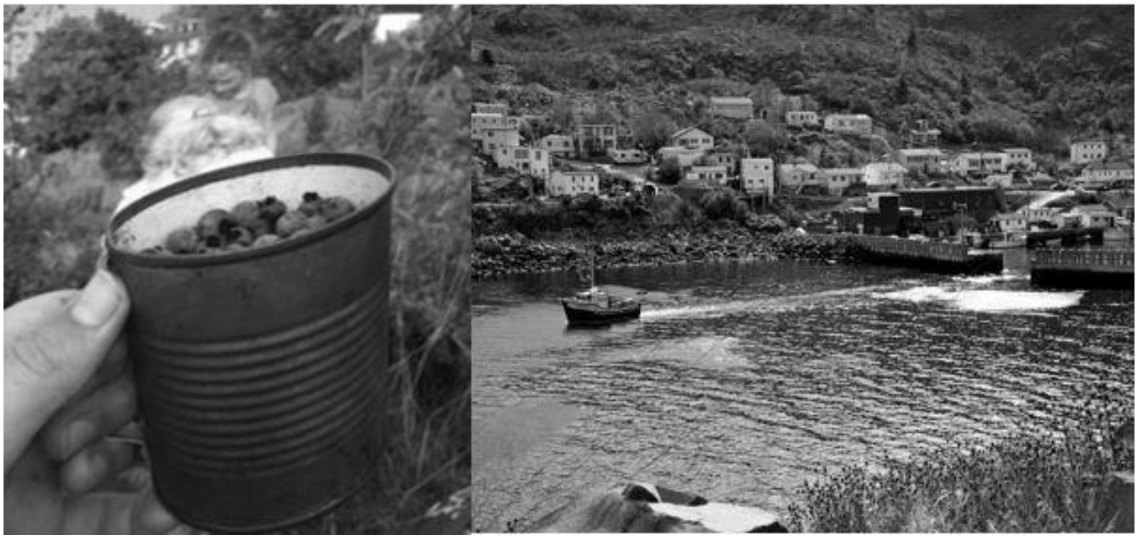


Plate 31 Photos from Isobel.

With this project I wanted you to catch a glimpse and appreciation of this special lady – my mom. I hope you come to understand caring is easy, it happens effortlessly without any asking. The burden of caregiving, on the other hand, is loss. Loss of time, loss of person and loss of perspective for all involved. Though constantly faced with loss, through this work I have found ways to rediscover the beauty, joy, and appreciation of what I have. I hope this is evident. Many thanks to Megan Morrison for providing this opportunity, to my family and friends for always being present, and finally to my parents for unconditional love... and the chance to reciprocate.

5.11 “Shared Times”

Plate 32   Emma's title card.

The next art piece sits on a baking tray placed on a wheelchair adorned with photos. On the baking sheet are partially dried dough creations. One of them resembles a person. Attached to the chair are photos of a woman. There is a coloured photo of play dough containers and cookie cutters accompanied by a handwritten recipe for homemade play-dough.

Emma’s Artist Statement

"What do I do now?" These words I have repeatedly heard uttered by my dear 86 year-old Mother whenever she is required to perform the simplest of tasks. It has been heart-wrenching to watch her steady decline into this unknown abyss known as

Plate 33 Emma's playdough shapes.

Alzheimer's disease. When first asked to contribute my experience as an occasional caregiver to my Mom, I was reluctant. After all, it was my Father who was Mom's primary caregiver for twenty-four hours a day for the past six years, up until his passing just this May. I decided to share my experience, however, in the hopes that it reaches someone in a similar position who is watching a loved one slowly disappear.

My Mother and Father have always been loving, generous, and involved parents and I grew up in a warm and supportive home atmosphere. When my parents became grandparents and retired, they moved to the city to be closer to their family and treated their grandchildren in the same caring manner that they raised their children. They attended every soccer game, hosted excursions around the bay, sang "Happy Birthday" the loudest, brought us berry picking complete with boil ups, and smiled proudly in the crowd at all recitals, confirmations and graduations. Not a week went by that they didn't spend quality, hands-on time with their grandchildren. As a compliment to that, I chose to use play dough for my creative project. This piece represents all of the past events that get discussed every time my Mom, and I do our "cooking" - using the soft mushy pliable dough to create colourful shapes.

I have witnessed many a smile on her face as she squeezes the dough and listens to my

A Recipe For: Playdoh
Ingredients 1 cup flour, ½ cup salt
2 Tbsp Cream of Tartar
1 Tbsp oil, 1 cup water
food Colouring
Method
Place all ingredients in a medium saucepan. Over medium heat keep stirring until mixture looks like a globby mess. Knead!

Plate 34 Emma's project materials and recipe.

retelling of family events. Sometimes I can detect a moment of recognition and connection in her eyes, but then it is gone. Fleeting that these moments are, I also observe my Mom's strength and determination at her attempts to model what I do with the dough. At the beginning of her illness, it was only her short-term memory that was greatly affected, but within the past six months even recollection of her past life has faded.

She will often look at me after I've mentioned her great-grandchild or some other somewhat recent life event and ask tearfully, "Where have I been all this time?" Through the squeezing, rolling, pressing and creating shapes with the dough, I try to ignite my Mother's mind, so that she might better remember the events I discuss as we play with the dough. She is not gone yet, and while she is here, I will do whatever I can to keep her memories alive, for her and for me.

5.12 “Carol’s Project”

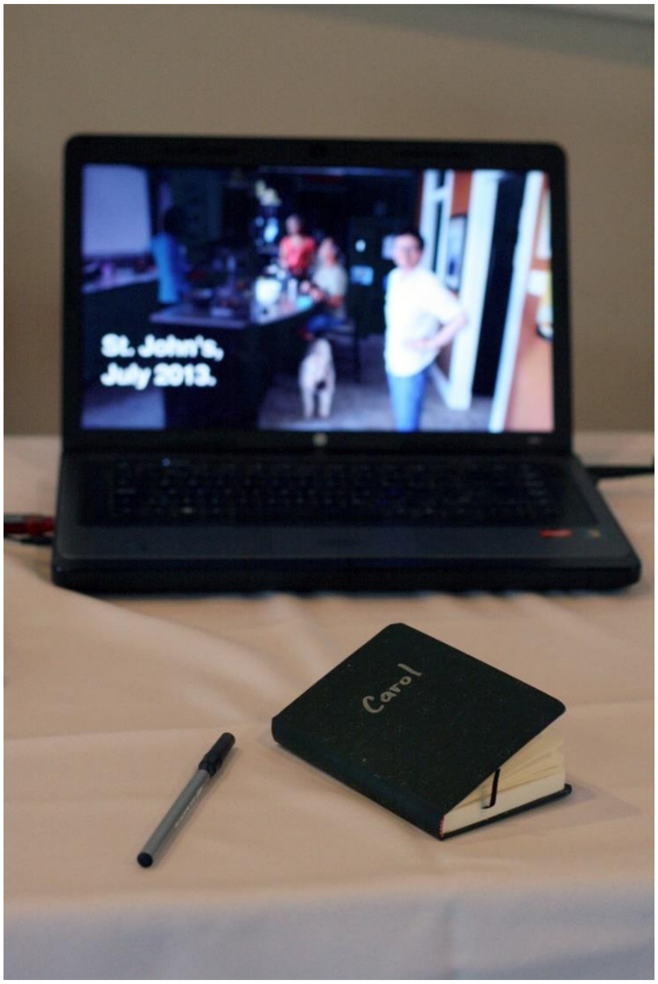


Plate 35 Tavish's video of family moments and a journal.

At the next table, Tavish and his spouse, Carol sit with their project pieces. There is a small wooden treasure box. Inside the box are photographs that Tavish took during his geocaching adventures with Carol. Next to the box of photos is a laptop with a still from Tavish’s film. The film shows Carol skating and other family moments together. The locations and dates are displayed across the screen as the images change.

Plate 36   Photos that Tavish took while geocaching.

Tavish's Artist Statement

I have been a full-time Alzheimer's caregiver to my spouse Carol since September 2010.

In this project, we have attempted to briefly illustrate our experiences, determine creative solutions to caregiving issues; define outlet activities that help both of us continue relatively normal lives; and, comment on the importance of the project to a caregiver.

My Experiences and Determining Creative Solutions:

Following a thorough medical assessment, my spouse was evaluated with Alzheimer's disease in September 2010. The outcome of the assessment, while not entirely unexpected, was devastating for both of us.

My wife suffered a deep depression for a short period of time and was eventually assisted through this with medical help. My initial reaction was shock, disappointment, bewilderment, and a sense of helplessness.

For some 7-10 days, I spent enormous amounts of time thinking about and planning how to manage this illness with a view to living relatively normal lives. I was at the very bottom of the Alzheimer's learning curve at the outset of this journey!

To my delight, there are innumerable resources available to guide one through this process. These included, but are not exclusive to; mounds of written materials, consultations with professionals at Alzheimer's Resource centers, on-line resources through various web sites; and, frequent consultations with my children and other family members.

As a consequence, we formulated a daily care plan which included regularly scheduled bathing and meal times, daily outings which had been an important element in my wife's daily routine, frequent visits to family and friends, shopping expeditions, ice skating, snow shoeing, regular vacations; and so forth.

Frankly, we decided to keep her daily routine "normal" and follow life style patterns to which she was accustomed and in which she would have a high comfort level.

As we proceeded through this Alzheimer's journey; personal behavioural and general care giving issues frequently arose! These had to be quickly and effectively dealt with without causing her undue stress or concern.

The resources previously mentioned were referenced for potential solutions. Where none were obvious; I was required to dramatically "think outside the box" and literally try what some might consider abstract solutions.

Family and friends were often used as "sounding boards" for potential solutions. A number of tentative solutions were complete failures! While not all solutions worked as effectively; we were able to collectively apply remedies that were manageable. In some instances, two or three efforts were needed before you actually "hit" the right fix! Additionally, frequent medical check-ups are an integral part of both her physical and mental care.

Consequently, my daily routine and lifestyle as well as my wife's, have not generated into the burden that one might expect!

Outlet Activities:

Apart from the routines previously mentioned; my wife and I have been actively engaged in "Geocaching"® for approximately 6 years.

A quick explanation for those who aren't familiar!

"Geocaching is a real-world outdoor treasure hunting game using GPS enabled devices. Participants navigate to a specific set of GPS co-ordinates and then attempt to find the geocache (container) hidden at that location". (Source: Geocaching Inc. web site).

This activity has allowed us to collectively share positive experiences. Due to her medical condition, my wife is not as enthusiastic about this activity as previously. However, it still provides her with ample positive experiences; and of particular importance, generous amounts of physical exercise.

There are parallels between her illness and Geocaching!

I will briefly elaborate on several of these!

- *The activity allows both of us to obtain a relatively "good dose" of physical activity. In some cases, lots of walking is required. Physical activity is an extremely positive element in an Alzheimer's patient's care and allows the caregiver to manage the patient more easily and effectively.*

- *Geocaching Inc. encourages all members to pick up any trash you encounter while participating in this activity. In that my wife was typically a "neat freak" (I say this in a positive sense); she delights in helping to keep the environment clean while at the same time commenting on why people would litter in the first place! Picking up the trash seems to increase her comfort zone with this activity!*

- *This activity is a journey! Finding the Geocache is a reward for the effort you expend. However, you encounter unexpected events along the way and the outcome may often be a surprise. Not totally unlike the "events" and "surprises" you encounter daily as an Alzheimer's caregiver!*

- *You typically encounter positive and unexpected events on your Geocaching journey! Examples would be viewing new scenery, experiencing scenic areas that you would probably never typically visit, receiving feedback from those who find Caches we've hidden, meeting new people as part of your "search"; and, sometimes disappointment with your inability to find the cache; and so forth.*

- *The Alzheimer's journey also offers new experiences, almost on a daily basis. You are often required to explore "new territory" to find creative solutions that assist you and your spouse in Alzheimer's caregiving.*

Project Importance:

There is no need to extensively elaborate on the significance of this Project. The benefits and outcomes are self-evident. It has provided an outlet to share my experiences on this journey.
I have endeavored to illustrate some of the "tools" which I have found effective in managing this illness.

It presents my experiences to others who can possibly derive a benefit as they make a similar journey. Conversely, it allows us to learn from the experiences of others.

Participating has been a delightful experience!

5.13 “Keeping the Faith”

Plate 37 Jack's title card.

A large piece of plywood sits upright with many photos attached. Jack took these photos as he documented the renovations in his home. On the table is a copy of a talk he gave to the community with his wife and then on his own.

I won’t give you a list of symptoms of the disease. (throw screwed up sheet of paper over shoulder). I won’t quote statistics about the disease. This sort of thing is available on the internet. (throw another screwed up sheet of paper over shoulder).And I can’t tell you what it’s like to have the disease. If you want more information on that, I suggest the book Still Alice by Lisa Genova or reading [my wife’s] presentation to the Alzheimer’s Society of NL soon after she was diagnosed.

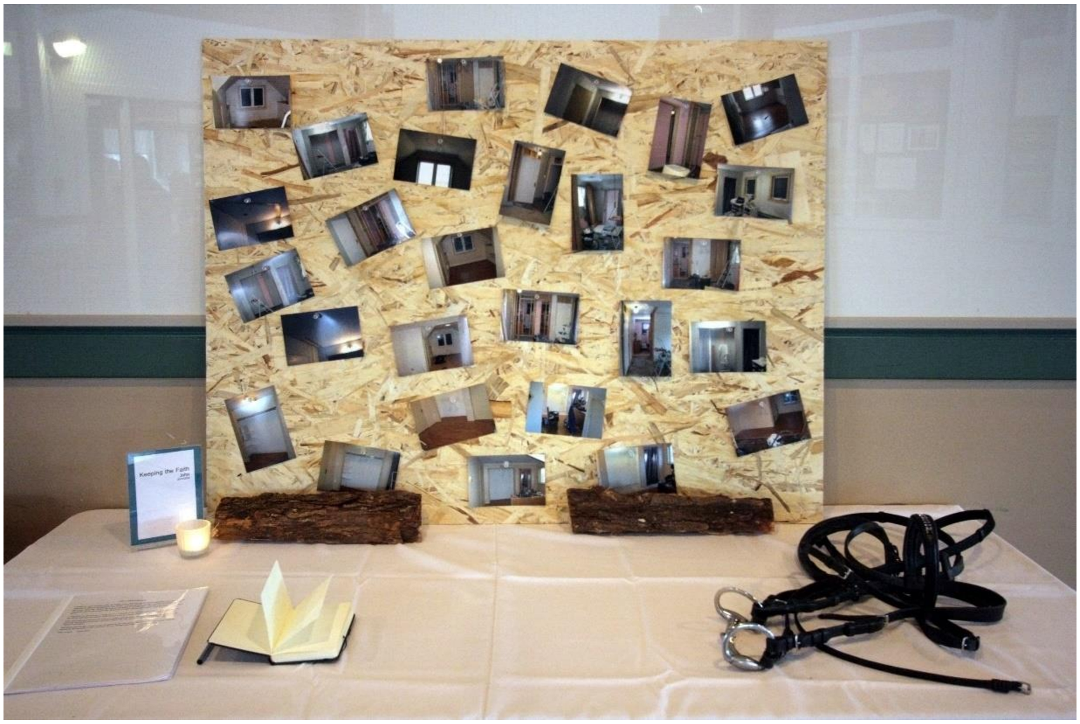


Plate 38 Jack's project.

Jack's Artist statement.

I cared for Carol at home until she began to lose her way in the house, especially at night. She was admitted to a long term care home, a secure facility, in July of 2010. I was able to visit her every other day. When she lost her mobility in October 2011 she was transferred to a place in Grand Falls-Windsor. I could visit her there daily until she died on May 22 2013.

Plate 39   Photos of Jack's renovations.

I wanted to do something to help those in a similar to position to Carol and myself, and I became involved with the provincial Alzheimer’s Society. I have given several presentations. Carol and I had done a lot of house improvements, and I decided to remodel our bedroom. It not only reminded me of our previous efforts but also meant a new bedroom for me in my changed situation. The horse and sleigh belong to my daughter in law but had no harness. I found I could immerse myself in the intricate work and found it very therapeutic when I was feeling low.

End of the exhibit

I took an opportunity to speak to those in the room and thank them for their presence. I was not able to express in words the level of gratitude I felt as everything, and everyone came together to share visible space.

Chapter 6
The Pieces We Came to See

Plate 40   Participants decorated puzzle pieces and then I pieced them together.

The exhibit added a genuine visibility to the caregiver’s stories. The exhibit is an intended visible space that not every person can avail of. Looking at caregiving through a creative lens gives visibility to the unknown aspects of the caregiving role. This study demonstrates that caring for a loved one living with dementia is at its core a creative skill. Creative skill is a part of everyday activity that is visible and well-documented, but it is also a part of the invisible spaces of caring for a family member. A family caregiver’s creativity is engaged in the initial stage because they are often the first and only person to notice. There is no single moment when a family member moves from the role of spouse or child to the role of caregiver. There are multiple significant and invisible spaces where creativity assists caregivers in navigating change. Creativity is an integral part of how caregivers navigate frustration, change and how they develop the patience and skills to provide person-centred care. Also, the caregiving role continues as care contexts/living contexts change.

I intended for this study to help others see caregivers' creativity in the invisible spaces as a form of artistry to demonstrate the beauty, strength, and skill in their role. I also intended for the exhibit space to produce an evolving and organic text that could share their skills with others. The meaning of the exhibit space began with what the caregivers made visual and evolved with audience engagement and response. By focusing on creativity, this study brings new understandings of caregiving as a work of art and illuminated invisible spaces. The participants introduced me to these spaces during our initial interview and expanded on their thoughts and feelings through their creative projects. The research as a whole presents how family caregivers use creativity in everyday care spaces not often visible to those outside the context. In this chapter, I present my findings in three parts. First, I highlight the spaces of care that this study makes visible. Second, I discuss how the participants made these care spaces visible and, third, I discuss the specific contribution to the participants and their families, caregivers and the community, and academia.

In this chapter, I discuss how my findings build on the concept of personhood by contributing the need for creativity. As Dewing (2007) outlines, many references to personhood are rooted in values that (in the western context) prioritize cognitive functioning for example, “…cognitive attributes that enable functions such as rationality, informed choice, decision-making and responsible action…” and places less value on “…attributes such as expressiveness or the ability to feel and express emotion and spirituality...” (Dewing, 2007, p. 6). This is why Kitwood’s (1997) five essential needs (comfort, inclusion, identity, occupation, and attachment) enable a family member to think of possibilities in providing support. There are studies that have explored family members’ strategies to provide person-centred care. For example Chung, Ellis-Hill and Coleman (2017) found that family members used the following care strategies: being nonjudgmental, facilitating a sense of worth, taking calculated risks, maintaining the continuity of their relative’s identity, enhancing a sense of connection with their relative’s role and identity using enjoyable activities, and preventing inactivity and attending to the bodily source of agency (p. 1) whereas Perry and O’Connor (2002) highlighted “maintaining continuity, supporting competence, protecting from incompetence, and strategizing encounters”(p. 60). We can see that over 15 years, the caregiving literature identifies similar strategies and they all attend to the personhood of the individual living with dementia. The following sections provide a similar snapshot of care strategies, but instead of focusing on daily tasks and isolated efforts, I am highlighting how the family member engages with creativity increasingly over time and as a mechanism to support their loved one in visible and invisible spaces of care.

Creativity is the core mechanism that allows a family member to provide person-centred care. The family member caring for the person living with dementia has traversed a continuous relational space where they have attended to the personhood of their loved one. Creativity is substantially absent in caregiving literature except for when it is about arts-based interventions to support the person living with dementia. While studies looking at care strategies allude to thoughts and actions that are creative through phrases like “adapted to the environment”, “adjusting the physical and social environment”, “find strategies”, and “created tactics” (Chung, Ellis-Hill & Coleman, 2017), the focus is on what is accomplished, not what is the mechanism behind it. Perry and O’Connor (2002) identified that for family members to continue with established care strategies, they would need to be increasingly creative with how they solve problems. The findings in this study provide a rich understanding of what it means to attend to personhood, the strategies behind this effort and creativity as the core mechanism behind the strategies.

The findings below convey how creativity is at the core of providing this care, that the family member develops an expertise in attending to personhood and that there is a potential for reciprocal contribution to how we understand the familial care role and person-centred approaches to caring for an individual with dementia through this creativity.

6.1 Invisible Spaces of Creative Care

In this first section, I discuss the invisible spaces of providing care to a family member living with dementia. These spaces include initial invisibility, heightened presence, navigating change, dealing with frustration and self-care, developing patience, continuous care, and maintaining relationship. While variations of these themes exist in other caregiving literature, one can learn even more through a creative lens. Each of these spaces builds on and adds to existing caregiving literature addressing several identified gaps and highlighting the needs for a creative lens to begin to fill them.

6.1.1 Initial Invisibility

Initial invisibility refers to the time spent together when the word "dementia" or "caregiving" have not yet been spoken. Other people cannot see this space. Each of the caregivers had a unique story about what they noticed first in terms of change. These stories are a testament to how family members have a person-centred approach to caring before they even see themselves as caregivers. This is significant because as stated earlier in this thesis, a person-centred approach attends to emotional needs making the symptoms of dementia less intrusive (O'Connor et al., 2007). Each of the family members' creative projects displayed the creativity involved in attending to their loved one's emotional needs and demonstrated what this looked like in the beginning. They noticed changes in behaviour, daily habits, and hobbies and broadly in their relationship. Caregivers recalled the changes in their loved ones that occurred gradually over time:

> *She used to do a lot of reading. I noticed that the reading was not being done as much. Then it got to the crossword puzzles, she was good at them and she would do them most all right away. I noticed things…she would always get up in the morning and make the bed you know, but then I noticed that the beds would not be made* (Forrest).
>
> *I knew that it was a little more serious than just forgetfulness when she stopped baking. My mother loved to bake. She always made lovely meals and made a lot of different desserts, she was always experimenting with her baking and then she just stopped. She would call me for a recipe. She would say "I cannot find such and such a recipe, and I know you have it, can you read it out to me". Well what should be a 20-minute task was over an hour, because she would say, now how do you spell that…To the point where she just did not ask for recipes anymore, until it advanced to the stage where she just stopped baking period* (Emma).

> *My wife had just turned sixty when she was diagnosed. I had had some suspicions prior to that, just one or two odd things. And really going back for two years before her diagnosis, with hindsight, I could see there was something odd in one or two things that happened* (Jack).

We used to play crib, and we used to play other games too, till he stopped playing, and then at the end of it, I would look in his hands to see what he had and tell him which one to play. Then I would say, "play a five", and he would play a king. That is how bad it got, but we still played right up until that time (Ren). In these quotations, one can see how everyday tasks or hobbies become symbols. The visibility of the symbol and its meaning is something that only the caregiver can relay. These narrative pieces point to the invisibility of initial changes. Caregivers find creative ways to change routine and make sense of new routine. The caregiver's ability to recognize change is a result of how well they know each other and being a part of each other's everyday lives. A person who does not have the same connection with the person with dementia does not have the same degree of awareness of past and current context. Within caregiving literature, there is a gap in insight into how family members sustain their loved one's wellbeing through everyday activities (Chung, Ellis-Hill & Coleman, 2017). This study suggests that a family caregiver's thoughts and actions are more than a visible task or a single moment, they are skills developed over time, rooted in previous knowledge of the person and sustained by creativity. The family member's knowledge of their loved one and their connection to the person invokes creativity as they experience a desire to attend to the needs of their loved ones in the face of change. This initial space and the transitions that emerge are the family member's unique knowledge, but as they develop their skill and attunement to their loved one's needs it can also be isolating for them.

6.1.2 Heightened Presence

A consequence of being the only person to recognize/attend to the individual living with dementia is that there is a heavy reliance from that person for the caregiver to be increasingly present. The literature looks at the demand for physical presence in terms of a person living with dementia needing reminders and guidance, engaging in repetitive conversation, shadowing, etc. and that this conflicts with the caregiver's chance to have independence (Jansson, 2001). However, as this study shows, the presence is based on an expertise in creativity attending to the person and the reciprocal exchange of affirming both person's identity and the relationship as a whole, The caregiver is gradually developing a new relationship where they attune their situation to what best meets the growing needs of their loved one. Attending to the five needs demands that the caregiver be increasingly present. In each of the caregiving narratives, the person living with dementia relied on their family member emotionally and physically. Rhona and Isobel share their experience:

> *He was shadowing me for at least 2 years or maybe longer. If I'd go downstairs he'd follow me, come up, whatever...he would sit there, and he would fall asleep there first watching me wash dishes…he'd be on guard if I moved, the eyes were open. He gets frustrated if I go out too much. He has lost all his independence, and he depends on me for everything* (Rhona).
>
> *It is always a stress trying to leave* (Isobel).

The caregiver becomes increasingly visible to the person with dementia, which increases the invisibility of their role to those outside the home. Ren describes her challenge with leaving home:

> *Everyone used to say, why do you have two cars? It is my babysitter. I can leave the house and go for a run around the pond…that was before he started following me, when he started following me I could not go an inch without him. Only when I had home care, and it was hard to do it then, I still would have to leave that car* (Ren).

This heightened presence means an increasing need for the caregiver to find creative strategies to attend to their loved one's emotional needs. The caregiving literature acknowledges that family caregivers are attending to the "functional, psychosocial, emotional and environmental needs" (Chung, Ellis-Hill & Coleman, 2017, p. 10) of their loved one, but there is not a lot known on the underlying creativity used to determine strategies.

6.1.3 Navigating Change

The caregiver becomes increasingly present (both physically and emotionally) when they use their creativity to navigate and adapt to change. Caregivers revealed that many of the changes they experienced were not visible to the outside world. I heard about how they managed to navigate through transitions. Each of the caregivers had a unique story about how they recognized change, and each of their creative projects displayed the creativity involved in managing change. They observed changes in behaviours, daily habits, and hobbies and the interactions within their relationship and used their creativity to find adapted and new ways to attend to personhood and ensure their family member felt loved. Many of the changes described were incremental. These changes may seem small, but they do require a shift for the caregiver. As change occurs, the caregiver gains additional responsibilities and responds with creativity. Some of these new responsibilities require physical tasks and others are emotional ones. One of the ways that Forrest addressed his wife's need to feel occupied when she was no longer able to do the crossword puzzle was by engaging her in music-making and dancing. These first transitions from previous behaviours is an invisible space that only family caregivers recognize.

> *There was foreign things in meals that she cooked that I was not….like stuff that does not belong in her normal soup would show up there. She might have salmon in her beef soup, and I am thinking, what is going on here. Slowly things have changed and now to the point that she is not even cooking at all* (Isobel).

Isobel attended to her mother's need for inclusion, identity, and occupation in her creative project by finding an activity that matched her mother's previous interests with her current ability to carry out a task. Parallel to the gradual changes, creativity also generates gradually. In many cases, for example with Ren, these changes were so gradual that friends and family would deny anything extraordinary was happening.

> *No one else would see it; people would come in and say, 'oh my god, he's perfect. There's nothing wrong'* (Ren).

> *Reading and stuff like that, it all went. It changed so gradually I could see it, other people could not, but I could see it* (Ren).

There are invisible spaces of care right from the initial changes in behavior. It is significant that even when caregivers try to communicate what they notice, it is not visible to others. In Jack's experience, the beginning stage was an invisible space even as he reached out to clinicians. The changes that occur are not only affecting behavior but also the relationship. Changes in relationship change the caregiver's narrative, which is easy to notice for the caregiver who is living it. The caregivers referenced changes to the dynamic in the previous state of their relationship. These narrative changes point to the role of the previous relationship.

The caregiver's ability to recognize change is a result of how well they know each other. A person who had not been a part of the person with dementia's life previously would not know the difference between previous and current behaviours.

> *My mom has a sister, who turned eighty this year. .... She just does not see that my mother is declining. She does know there are some issues, but she just does not see the decline. She is not there every day.* (Isobel)
>
> *No one knows the things that I do, even with the cooking and the baking. You know I give away a lot of it, but I am sure lots of times they don't even give it a thought, how much work was put into it. Some of my friends sometimes, don't think that I did it* (Rhona).

Once those outside of the relationship (i.e. family and friends) do notice change, there are additional pressures on the caregiver to tend to those needs as well. Emma talks about others being fearful and leaning on her for support.

> *They knew that she was forgetful and whatnot, but I think waking up to the realization that she does not know how old she is anymore, or the year she was born, or you know…it is a little bit frightening for them. So they are leaning on you, or questioning or challenging you and your personal assessment.* (Emma)

As change becomes more visible to the outside world, this can initiate further change for the caregiver. Caregivers commented that in some cases, friends stopped coming to the house to socialize. This affects the caregiver as they find creative ways to navigate how to attend to their loved one's need for inclusion and attachment.

> *We had two other friends who used to come every Saturday and play pool with him, but since he has gotten like this, they have sort of gone their own way. They do not call or see how he is or anything anymore* (Rhona).

It can also mean further isolation and therefore, invisibility in their life. Hayes (2011) conveys that "[w]e need to be able to accept the various and complex emotions which occur beneath the surface of the human being. In dementia, emotions are nearer the surface because the veneer of social conditioning is thin" (p. 43). The change in relationship is the most significant ongoing shift, "there is a whole emotional shift from what you had into a whole new relationship and much more responsibility" (Janet).

6.1.4 Dealing with Frustration and Self Care

When a family member's presence is in demand, and much of their context is invisible, there can be many moments of frustration. Caregivers expressed different creative ways of dealing with these frustrations while still attending to their family member's need to feel loved. Some caregivers talked about humour as an effective means to turn a moment of frustration into a moment of connection:

> *I know it is terrible, but you know, we get a lot of laughs out of that too. Not being mean, but just, you know, taking light. (laughing) My nephew was here for Jim's funeral, and then my son could not wait to get for him to go so he could imitate him, and of course we cracked up, and he was constantly doing some imitations of someone, which made us laugh and got us through everything, you know* (Ren).
>
> *When you are in the moment, you just, you probably make a joke out of it, you know, oh mom give that to me, and I will make that smaller, you try not to…you would not criticize her for doing that* (Emma).

Another participant emphasized the importance of exercising:

> *I am a strong person, and I never get stressed, and I never want to take a pill for it no matter how bad things get. I get my shoes, and I go, or I get my swim bag and go – and that is my way of coping* (Ren).

Ren pointed out that she did not even realize the stress she felt. The spaces of care can be invisible to the caregivers themselves as they focused heavily on the needs of their loved one:

> *Well I suppose you do not really realize you are doing all this stuff, but I think that I, you know, started doing everything with him in mind* (Ren).

Dealing with stress also means anticipating stress and finding ways to avoid it:

> *So I find I have to be creative in keeping things calm and settled and not upsetting her. So I find I am making up stories that way* (Isobel).

Some caregivers emphasized a need for self-care:

> *The first thing you do is look after you. That is the number one job. And the best way for me to do that is just to maintain the lifestyle that I always had. I do not need to make any dramatic changes. It takes a little longer to do certain things, and maybe we do not do them in the same amount of enthusiasm. There is a couple of things I have had to give up, but I gave them up voluntarily. For example, I used to bike 15-20 kilometres every day. I do not do that anymore. The alternative? Go out and buy an exercise bike, which I have under my chair. So there are alternatives. I do not have to give up biking; I just cannot do it in the fresh air all the time* (Tavish).
>
> *During the two years I had people here, I used to take a break on weekends. I had to take a break, because I realized if I did not take a break, I would be going downhill myself. So I would take a break, maybe go to the cabin, go out on Friday, come back Monday* (Forrest).
>
> *I either run or do some form of exercise. I have to run at least three times a week to clear my head. So I draw on that myself* (Isobel).

Where Isobel took time for herself by leaving the house for small amounts of time, Forrest took one or two days with few breaks in-between. For Forrest, his cabin was a place he could be outdoors and re-gather his strength:

> *I used to take a break on weekends. I had to take a break, because I realized if I did not take a break, I would be going downhill myself. I garden, I had a little garden going out there. I had some trees and some flowers out and weed them, and cut the grass. Always cutting the grass* (Forrest).

Self-care is not just a concept but an action. Annie said, “I think [caregivers] need to be helped with tools, helped with understanding both themselves (because they are going through sheer hell at times) and understanding how their own life is shifting”.

> *…things went so slow, it is like you start wearing away and you don't really know that you are, you know, it just goes so slow, so slow* (Ren).

The caregivers who were able to take time for themselves reflected positively on that time as something which helped them to notice their own needs. In some instances, where self-care was not enacted, the caregiver’s health and well-being suffered. Amelia described reaching a threshold where her health had to take priority because she was providing care to her mother and her husband at the same time:

> *[I was] taking care of it day by day, and then I got breast cancer. I had to go in for surgery, and they still could not find a place for her. So I said to them, I am just going through my surgery, I am going to [the hospital], so I am just going to bring her up when I check-in in the morning, and I am just going to say ‘I have nobody to take care of her. I can’t do anything.’ I was panicking because my husband could not take care of her, and my daughters by that time were away, and they could not take care of her, and I had to go for cancer….and I was panicking* (Amelia).

For Amelia and for others as well, “coping” is something where you hang on and provide care until there is no way you can do it anymore. Rhona had a similar experience where her health was suffering. For Rhona, the stress of caregiving exacerbated her health issues:

> *I went up there three times, and I saw the neurologist just up there. She said, "how in the world did you ever go through two years, suffering with that pain? And looking after the problem that you have at home?" and I said well I guess you do what you have to* (Rhona).

Rhona communicated that she only knew baking as a stress-relieving activity:

> *I do not know how to relax. I take out the bowls and the eggs and the flour, and I bake all night long* (Rhona).

Caregivers communicated that because of their care responsibilities. There was very little time or energy for activities they might enjoy:

> *I think I could create some great pictures, but I just have not had the time. I've been too busy with him in the past years that I... by the time I'm at the end of the day, when I can sit down for a minute, then I have lost it* (Ren).

Much of the literature on the benefits of creativity deals with how the caregiver attends to the personhood of the person receiving care or employing the arts as an intervention with the individual living with dementia. For example, Hayes (2011) suggests that the arts can contribute to persons with dementia by providing a "vehicle for self", a "relational bridge" and "healing" (pp. 32-34). I see potential for the same benefits for family members as they engage in creativity in their everyday lives and this project specifically as they use the arts to share their experience. Hayes (2011) states that "[t]o be able to work in a creative way with people with dementia we first have to free our own creativity" (p. 39). This study's findings affirm that the arts have benefit, but it expands how artistic products and creativity can be engaged in the context of dementia and family caregiving. Hannemann (2006) suggests that the act of being creative "…has been shown to reduce depression and isolation, offering the power of choice and decisions" (p.62). Using creativity to support a family caregiver can have these same benefits most often studied in relation to supporting the person with dementia.

6.1.5 Developing Patience

Participants explained that dementia requires a different level of patience and communication and there is often no verbal acknowledgment of how much a person puts into caring for their loved one. There is little to no recognition of the caregiver's creativity in developing patience. Tavish stressed the importance of letting go of expectations of communication and learning a new patience:

> *The biggest problem was, for me, learning, after being together for 50 something years, having been alive for 60 something years, I had to learn how to be patient all over again* (Tavish).

In learning this new kind of communication and patience, one develops a space of interaction that does not look the same as before. Tavish says, "I stopped arguing. I stopped trying to rationalize. It made my life, the stress, a lot easier". Rhona remembered the first time she lost her patience with her husband and found gratitude in herself for his patience:

> *I think the very first time that it happened I just snapped the head off of him, because I did not realize what was going on, because that had never happened before. Then, after I realized what I had done I went out to him, and I said, "can I have a hug?" He said, "what brought that on?" Well it was afternoon, and you were not very nice to me, and I snapped at you instead of doing what I am doing now. He said, "That's alright, we all have our days". I just looked at him, and I could not believe what I was hearing. Then of course I realized that just in that second, he was the man that I always knew. I find that my patience is giving out compared to what it was, because I have had this for four years* (Rhona).

Amelia explained that it took her a while to stop looking for acknowledgment from her mother and that this was one of her greatest strengths. Amelia shares a story from caring for her mother:

> *I remember one time bringing her this beautiful cheesecake, and it was all decorated. Take that back she said, and cook it, it is not even cooked. She loves cheesecake, I mean it was a real highlight, I mean I love cheesecake to this day. Who does not? But anyhow she could not comprehend the texture of it, because it was different from other foods, it's not a cake, but it tastes like a cake, it's not baked there's no form to it. She could not get that straight. You know, you are doing all this work, not that you want a nod of approval, but everyone wants something when they give out—acknowledgment* (Amelia).

Amelia's story shows her reflections on a moment where she felt unacknowledged. She suggests that the need to feel acknowledged is universal. Other caregivers shared similar sentiments. Acknowledgment is another component of support for caregivers that relies on someone other than the person receiving the care. Caregivers recognized their patience in adapting to newly defined (or reversed) relationship roles:

> *I had to decide whether I should do the cooking and risk upsetting my wife – because she'd always done it and she wanted to do it – or allowing her to do it and her getting upset because she couldn't manage. I found that quite difficult to do (Jack).*
>
> *The roles have switched because at one time he was my protector, and now it is almost as if I am moving into the role of protecting him (Emma).*
>
> *Like a mother you are always on call. So you lose your spouse and gain an elderly child. So there is a whole emotional shift from what you had into a whole new relationship and much more responsibility (Annie).*

6.1.6 Continuous Care

Especially in spousal dyads, caregivers expressed the desire to care for their loved one without intervention. These feelings were mostly rooted in the desire to keep their partner at home. This study reveals that although paid care interventions aim to relieve the pressure on the caregiver, this is not as simple as one might think. Overall, family caregivers are still caring for their loved one in and around paid care. Baumbusch and Phinney (2014) suggest that even when family members "…are visiting/visitors, they are tending to personal, social, emotional, physical needs" (p. 75). The family caregiver is highly attuned to what personhood means to their loved one, and they establish creative approaches to responding to their loved one's needs. This skill continues across the care trajectory. We can see this continual care role in a variety of examples. In the context of a paid caregiver coming into the home caregivers can find themselves training and monitoring the paid-caregiver to ensure their loved one is cared for adequately. Forrest expressed how he was the only person who could read his wife's face. Many times, he found himself helping paid caregivers to "read" his wife. In the later stage of her dementia he was the only person able to determine her needs.

> *I knew my wife pretty well. She knew me really well. If a new girl came, I would say look, you see that? She wants to go the bathroom, so take her out of the chair and take her to the bathroom. She wanted to go…*
> *Six months before she died, the girls had to ask at that time, but I knew. She would sign that she wanted to go to the bathroom, and I could tell by looking at the expressions on her face. I was able to detect things with her, knowing her for forty-odd years that others could not detect* (Forrest).

Another example is that an individual living with dementia has relied on their family member for such a significant length of time that they may refuse the discomfort of someone who cannot attend to their personhood as well. For the caregiver, they may face feelings of fear and anxiety around how their loved one would react to paid care and in turn, what kind of attention to personhood (or lack thereof) would result.

> *I started homecare last year in January. He would say, "What's that arsehole doing?" and he would be putting a fist up, you know, "What's that arsehole doing here?" and he would be so mad. I would think 'oh my god, I suppose he will be okay with my young guy that came'. I would be a little bit worried, but when I ask him when I came back he said, "oh my, he was good as anything, good as anything." But you know, he wouldn't eat for him, you know, he'd get him some lunch and I'd say, "He's going to get you lunch now, Paul's going to get you lunch, and you'll have a cup of tea or coffee, -he would have that- but he wouldn't eat, he'd be so mad that I'm gone out* (Ren).

In this context, the family member feels responsible for both the paid caregiver and their loved one's experience. The person living with dementia may interpret paid-care as taking away from their personhood.

> *I would love to have somebody come and clean the home. It is mostly that kind of thing that I notice dramatically, and she refuses if you get somebody, "if you bring somebody into this house, I may as well not be alive*" (Isobel).

One caregiver spoke of having a paid caregiver "shadow" her for a month before she was able to take a break.

> *Leading up to that holiday, I had to make sure there was a caregiver there doing exactly what I was doing for my mom. I was fortunate in that my older sibling had a contact and so that person shadowed me for about a month and then I felt very at ease when I left. If I never had that support, it would have been really difficult to leave. You know, you feel guilty when you go away. You really do, even when you do not visit for a day, you feel really guilty* (Emma).

The above quote conveys the significance of family caregivers' expertise and the emotional connection woven into it. The person living with dementia does not always express this emotional connection. Still, in many cases, the family member continues to provide care without recognition adding further invisibility to the caregiver.

> *She went to the stage where I would care for her and she did not know who I was. Then she said, I am some glad you were not that other one. I was the only one. This would be all weekends and evenings I would be doing that. It was for a*

> *certain period when she got that bad that she needed 24-hour care. It was really bad. She would be sweet, and she would call up the police on the phone. She would be calling up the police and saying, "get me out of this place, I don't like the woman who was here"* (Amelia).

The role of family members across different care landscapes is relatively absent in caregiving literature. There is acknowledgement that care landscapes change and that emotional proximities are not necessarily related to physical ones; however, the interaction between a family member and their loved one living with dementia across different care contexts still requires further exploration to understanding what is involved. The role of the family member once their loved one has moved to long-term care, in particular requires further study (Baumbusch & Phinney, 2014).

6.1.7 Maintaining Relationship

For all of the participants, a relationship existed before the care context. For family caregivers, attending to personhood also includes using creativity to find ways to maintain their relationship. Kitwood's (1997) five essential needs, focus on the needs of the individual living with dementia. The family caregiver also holds these needs and finds ways to attend to them in the context of the preexisting relationship. There is mutual benefit through attending to personhood. Perry and O'Connor (2002) state, "…when spouse caregivers, preserve the personhood of their partners, they also preserve their own identity as husbands and wives. The overall goal of preserving personhood appears to benefit both spouses" (p. 60). This is not only true for spouses but child/parent relationships as well. One of the ways that caregivers maintain a sense of continuity in their relationship is through arts-based activities. These activities included taking painting classes (Linus, Annie), fiber-arts (Annie, Amelia, Isobel, Ren, Rhona, Emma), writing poetry (Linus, Luke,) and singing/song-writing (Isobel, Forrest). Although these participants had experience with particular arts-related activities, many of them found themselves putting their creative interests on hold. For those participants who experienced an absence of arts-related activity, the project provided an opportunity to re-engage.

> *She liked playing [the piano.] Even when she had dementia, she could still play the piano there. That's a piano keyboard on that, that's a real organ. That's over a hundred years old. She could play….there are pictures of her and me, she would play with me looking over her shoulder singing. When the song is playing on the radio, on the tapes, I would sing along, and she would mumble along with me. She still understood there until about six months before she died. Six months before she died she wasn't understanding what she was saying…I had a chair at that time (*Forrest).
>
> *I have noticed, and I know children help my mom be herself and music helps her be herself* (Isobel).
>
> *An artist, I think, must have a sense of excitement, of 'oh my goodness, I can see how I can do this. I know that I can do this. I know that I can write this piece of music. I know I can do this drawing or this painting.' I think there's a sort of excitement that you have the ability to do it, without feeling, necessarily, that it is something particularly unusual, although other people might see it like that* (Jack).
>
> *Okay, so you are going to take your husband for a walk, but you could have also been preparing a surprise picnic with little things to open up as well. You know. Supposing you told your person you were going to go for a walk, but then you go down to Bowring park, and you open up your hamper, and it could be anything from blowing bubbles to…. when he is kicking you in the shins in the middle of the night, you have to be creative* (Annie).
>
> *There are alternatives. You just have to figure out, Okay, what's the alternative to doing what you used to do. You can't do it the same way you did it for years, but what's the alternative? What's another way to do the same activity? You get a little bit creative sometimes* (Tavish).

> *As time went on of course he'd be constantly poking me, he would wake up, you know, when he got worse a couple of years ago I suppose, he was at that 2 or 3 years, he would poke at me to see if I'm in bed. So each time he did that he would wake me up. And sometimes I'd get back to sleep right away, and other times I wouldn't, cause I'm a good sleeper, but you know, sometimes you wake up, and you're wide awake and um, then what I did was rolled up a blanket... I rolled up a thick blanket, and I put between us* (Ren).
>
> *I still have the marks on the cribbage board. He couldn't figure out which direction to go in Cribbage, which we had played for years. So I had to put the marks and which way to go (Annie).*

The participants used their creativity to maintain a connection to their relationship before dementia. This ranged from finding ways to include their family member in family traditions and maintain relationships with grandchildren to making supper. Kitwood (1977) says,

> …in the ordinary settings of everyday life, the ability to include those whose mental powers are failing has not been well developed. The result is that people with dementia often have no group to belong to not even the family of which they were once a part (p. 20).

Everyday creativity is used to find methods of adapting to change and yet keeping some things the same. Chung, Ellis-Hill, and Coleman (2017) found that caregivers were "maintaining previous identity" while experiencing "complex and constant changing circumstances" (p. 10). The caregiver is pulled in more than one direction as they feel their previous relationship and their present but changing relationship in conflict. Kitwood (1997) states that occupation can be something someone does by themselves or with others. He also states that "[i]t requires a great deal of skill and imagination to meet the need for occupation, in a way that does not impose false solutions, crude and readymade" (p. 20). Kitwood's words emphasize that caregivers are doing more than keeping their family member busy. They are finding ways to make tasks meaningful whether it is through time together or separate. The caregivers in this study stressed the importance of maintaining the relationship itself and finding new ways to redefine it.

Davies and Gregory (2007) suggest that in caregiving, the “marriage biography” has a significant role in how dementia affects the relationship and how the two individuals adapt. Although the caregiving dyads in my research are not all part of a “marriage”, the caregiver and care-receiver have individual identities that have a significant impact on the care context. Research that acknowledges the relationship between caregivers’ and care-receivers’ needs as a duo is greatly lacking (Keefe & Krawchenko, 2015). Each caregiving context is a “figurative” marriage, if not a real one. Davies and Gregory (2007) explain “…the marriage relationship shapes the contours of the dementia landscape” (p. 483). Whether caregivers were making adjustments to their physical space or their expectations, they found new and creative ways to care for a family member with dementia.

6.2 Making Spaces Visible through a Creative Lens

Each caregiver had a unique approach to making their caregiving role visible. This section talks about how participants engaged with metaphor, symbol, and imagery within the exhibit space. These elements are essential as they draw attention to the point of connection within each creative project that allows the audience to engage with more than words and to see how the invisible is made visible through creative means.

6.2.1 Metaphor and Symbol

Many of the symbolic elements throughout the exhibit relied on everyday objects and situations that are easy to identify. The use of familiar symbols creates a bridge from observer to artist. This bridge allows observers to find points of connection and empathy even though they may have no experience with dementia. The metaphor "dementia is like a window that opens and closes" draws the audience in and causes curiosity. Ren indicated that sometimes she felt she was able to communicate and connect to her husband easily, and other times it was difficult. Ren's creative project provided a physical representation of this metaphor. All caregivers described dementia-related symptoms as unpredictable in presence and magnitude. Ren's window includes embroidery, which is a reference to her interest but lack of time to devote to the art form.

The rooms in Jack's house show walls taken down, newly built elements, protective coverings and tools, all used to re-envision his life between four walls that are now his own. The metaphor communicates that caregivers are often renovating space within the caregiving context. Once a renovation has occurred, what existed previously may not be visible to anyone else this can be especially hard on caregivers as they experience change regularly in the context of dementia.

Amelia felts her wool to all different shapes and sizes, in a vast array of colours. In the end, she has a new hat. For Amelia, these hats are a metaphor. Different hats mean different feelings. Family caregivers adapt to shifts in emotion and behaviour throughout their journey; theirs and those of their loved one living with dementia.

Luke represents the significance of music in his narrative in permanent ink written on an old guitar. In his experience, music represents a connective bridge between generations and a symbol of healing and legacy. Luke was not the only one who made connections to music. Multiple participants mentioned music as a space to connect in one way or another. Music transcends the need for coherent conversation or instruction. In Isobel's project, she allows her bare voice to communicate the shifting context for making music. What was once a predictable ritual between mother and daughter is now a new space where her voice is sometimes all she hears. Forrest highlighted music as a way of connecting to his wife and like Isobel, said while he had to adapt to a shift in musical roles/responsibilities the symbolism of the moment shared carried on. Rhona recognized a way to take advantage of her husband's forgetfulness in a way that benefited both of them. By asking her husband to play piano (even when he had already played), she was able to maintain continuity in that part of his identity.

While music was a prominent symbol, the exhibit presented an abundance of others. Ren saw her husband's love of the crossword puzzle and adapted as his skill or interest shifted. This symbol held such meaning that she found comfort doing the crossword puzzle when he no longer did. Linus maintained a connection to his mother through artistic interpretations of his experiences in honour of her artistic accomplishments earlier in life. For Linus, the arts were a way of honouring his mother even after she passed away as he continued to make meaning of their experiences together. Emma shared the symbol of baking. The flexibility of dough and its outcomes allowed Emma to show how she has adapted to her mother's changing skillset while maintaining a connection that is deeply rooted in her past. Jack found a connection with his wife by being around horses. While he adapted riding in numerous ways, his attachment to the symbol was evident in how he maintained the presence of horses in their relationship. These are only a few examples of the meaningful symbols that emerged from this study. Chung, Ellis-Hill, and Coleman (2017) also documented the importance of how caregivers "…tried to find the symbolic meaning of their relative's action as a way to make sense of how they could support their relative to engage in activities that appeared to be meaningful to the individual" (p. 8). How these symbols are meaningful for the participants contributes depth to our broader understandings of providing care to a family member living with dementia. Symbols help caregivers to adapt to change and maintain continuity in their relationship. These symbols can bring comfort through their historical meanings and bring new meanings to a changed relationship. Just as Luke's guitar holds permanent writing, caregivers hold permanent attachment to the symbols that connect them to their loved ones.

Tavish entered the exhibit with his head held high, and his arm linked with Carol. It was important to him that she attend and that they stand next to the creative project together. The physical presence of someone living with dementia and her/his family caregiver brought a unique dynamic to the exhibit. Their presence together demonstrates how family caregivers have an intimate knowledge of their loved one. Tavish engaged in conversation with strangers throughout the exhibit, and he had a way of responding to his partner that was a part of the exhibit itself. When Carol wandered away, he gave her space with a kind glance to check in while he spoke about his experience. At one point, she was standing alone, and he responded by greeting her lovingly and linking arms again. Their physical presence together was an incredible gift to the exhibit.

6.2.2 Imagery

Each participant chose photographs to accompany their creative project. Many of the projects were about moments. While each caregiver wrote an artist statement, they chose images to represent their relationship and the creative process. In some cases, the photographs made their creative process visible, and in others, it was a way of making their relationship more visible. There was also much overlap between the two as the process was indeed about their relationship.

Tavish’s project was about geocaching with his wife, but it was also about spaces that are conducive to getting fresh air and exercise while enjoying time together in the context of dementia. His artist statement addressed the symbolic elements of the process, but his photos made he and his wife’s moments together visible. In the photos, one can see the relaxed and content expression on his partner’s face, the birds and animals they came across, and one can almost feel the fresh air and open space that allowed the activity to happen. While Tavish’s writing communicated that geocaching was an activity that held benefit, the photos allow us to see how the process might look and consider how it might feel.

Emma and Isobel’s projects also included images. Isobel chose images that documented moments between her mother and family members. Among these photos is one of her mother sitting nearby while Isobel plays the piano and also one of a birthday celebration with grandchildren present. These photos and others played in a slideshow with the audio of Isobel’s voice. Isobel’s song communicates the strength required to care for a family member with dementia and the images shows moments of connection between family members. In Emma's creative project, imagery served a different purpose. She contributed photographs of her mother to accompany the other elements of the project. The baking sheet, the wheelchair, the playdough shapes and the photographs communicated that the person with dementia is still a person. Her mother's beautiful outfits in each photo show Emma's attention to her mother's identity. Jack also illustrated the importance of recognizing personhood by including photographs of his wife with his project.

6.3 Significance of Visibility

The participants' individual and collective contributions highlight the various invisible family caregiving spaces and the potential for knowledge transfer in separate but related spaces. The participants shared creative examples of care and harnessed their creativity to make their role more visible. Milligan and Wiles (2010) suggest, "care is woven through the fabric of particular social spaces" (p. 749). It is essential to understand these spaces from a family caregiver's perspective as there are multiple spaces where the social is limited to the person living with dementia and their family carer. This section presents the impact of "bricolage" (Denzin & Lincoln, 2011, p.4), or, all the representative pieces the reader has come to know. I discuss what this visibility can mean to different communities: participants and their loved ones, caregivers and the community, and research and researchers.

6.3.1 For Participants and Their Loved Ones

6.3.1.1 Space to Explore/Present Creativity

A significant contribution of this study is that the participants gained space for their creativity. Being creative in a caregiving role means imagining how to make a situation different and finding ways to adapt to change. I asked each participant to provide a few examples of their creativity. Some presented their artwork and did not immediately recognize the creativity in their caregiving role. Some presented their creativity as a caregiver, but did not recognize themselves as creative as they had not previously produced art. Participants talked about creativity as a hobby, time to one's self, stress-relief, something that helps one be present, helps preserve their dignity, helps their loved one feel useful, helps deal with frustration and anger, assists with decision-making, makes adaptation to transitions easier, promotes personhood, and allows one to make something beautiful out of their journey. Each caregiver/artist engaged with a different form of creative expression. The flexibility in choice of form was essential in finding and producing deeper meanings from words spoken in the initial interviews. If one thinks back to Cole & Knowles' (2008) ideas about what it means to be human and that each person has "myriad ways of engaging the world – oral, literal, visual, embodied" (p.60), the myriad forms of expression in this study have provided a deeper understanding through the same myriad ways of experiencing caregiving. Some elements of the artistic expressions emerged naturally from a hobby already developed by participants and came out of an interest in something new. I anticipated each project to be unique. However, the creativity that emerged and the different forms of representation blew me away. Each caregiver had a diverse perspective, which contributed to a unique approach. In these projects I saw photographs, poems, short stories, journal entries, woodwork, comedy, multi-media, play-dough, renovation, geocaching, and song-writing all communicate something unique about caregiving and about creativity in that role. The exhibit allowed the participants to take their creativity further by using a creative process to share their experience and knowledge with others. There are multiple benefits in using the arts to inform knowledge. Eisner (2008) suggests that through the arts we can learn the "qualitative nuances" of specific contexts, generate empathy that inspires people to act, provide a new understanding of spaces that would otherwise be invisible, and that the arts provide an avenue for reflecting on our life experiences. The present study exemplifies these concepts. The process of turning one's caregiving experience into a communicative, evocative and artistic form contributes a deeper understanding of the context of caring for a loved one with dementia, made visible spaces that were otherwise only spoken/written about and provided community engagement. In this process, family members also came to know their creativity in a new and uplifting way. Eisner (2008) states "[a]rt helps us connect with personal, subjective emotions, and through such a process, it enables us to discover our own interior landscape" (p. 11). For some it was an affirmation that their creativity existed and for others it was something new to explore. Each project combined imagery, metaphor, language, and story in an organized exhibit of the caregivers' strengths in caring for a loved one with dementia.

6.3.1.1 Link Between Creativity and Personhood

This study contributes to the field by demonstrating how creativity is central in providing person-centred care. By drawing attention to the everyday creativity and family care role, our understandings of both evolve. The big picture if we look at the themes presented in the interviews alongside the creative projects is that much of family caregiving in the context of a person living with dementia requires creativity because of the complex entanglement of physical and emotional needs. While many studies stress the importance of a person-centred approach in paid care roles, two areas are not well studied. First, this study's findings expand what it means to provide person-centred care by including creativity and making it visible through the arts. Second, this study's findings suggest that family caregivers already informally contribute to person-centred care but have the potential to shape all types of care provided to those living with dementia by including their expertise. When family caregivers are adapting to transition and change across the dementia-stages what they are doing is providing a bridge between their loved one and person-centred care from professionals. Formalizing this collaborative approach to care and increasing the visibility of invisible care spaces might allow caregivers to experience the same benefits.

6.3.2 For Caregivers and the Community

6.3.2.1 Visibility

The exhibit created a space within the community for creative learning. While appreciating works of art, individuals came to appreciate the contribution of caregivers but also to connect to the work. Roberts, Camic and Springham (2011) state that viewing art provides an "emotional, aesthetic and educational" opportunity for growth.

The exhibit encouraged people to use creativity as a way of illuminating the unseen and unconsidered aspects of caring for a loved one living with dementia.

Everyday spaces of caregiving look differently through art. In the exhibit space, caregiving knowledge becomes visible outside the family, the medical office, and the support group for broader engagement and appreciation. Those who attended the exhibit carry pieces of understanding with them when they leave. Community members engaged with and added to the exhibit by providing their responses in journals. The exhibit began as a venue to display caregiving as a work of art and evolved as a creative learning space, as evident in the feedback. The exhibit engaged participants and audience in a range of points in the caregiving journey, caregiving relationships, creative expression, and opportunities for creative engagement with individuals living with dementia. The exhibit provided a space for caregivers to feel connected to their own story in a unique way. It also provided a space for connection to other caregivers. The exhibit space communicated to the community that the act of caring for a family member with dementia is not an isolated experience but a unique and emotional one that caregivers communicate beyond words alone. The space provided for participants to "create" their narrative was flexible and encouraging of diversity. The most significant contribution of this study is visibility. The participants were able to see their creativity and the extent of their care role. The self became visible to the participant. They also gained visibility to the community through physical presence and experiential components of the exhibit. Their contribution also gained visibility to other caregivers as a contribution to the literature.

6.3.2.2 Connection with Others

The exhibit was a singular place where viewers could experience and respond to a multiplicity of caregiving experiences. In the context of this study, the exhibit provided a point of connection between participants and other participants, caregivers, and other caregivers, caregivers and community, and caregivers and academics. While there are many commonalities in the day-to-day tasks of a caregiver, the emotional requirements of each individual and the caregiver's response made caregiving for a loved one with dementia unique from family to family. Each participant's unique circumstance and experience can provide what Leavy (2015) refers to as "micro-macro connections". All persons who wrote in the feedback journals found a point of connection. As one caregiver wrote,

To my surprise, the multiple techniques used by other caregivers to manage their way through their lives was a unique experience for me. It ranged from relatively simple techniques to those where caregivers indeed played a very pro-active part in ensuring a sustainable quality of life care for their loved ones. The caregivers, as well as community members, felt moved by the artwork and the messages gathered. Most of the comments from the audience conveyed a moment of personal connection. Some of these comments are below:

> *My mom had cancer for a number of years and to see the effect on my father after 50 years together. Their six children of which I am one. Our love of each other stems from them. Our joy in our families is their legacy, and I thank you, Luke for helping with this new perspective.*
>
> *Those fleeting moments of recognition. I remember thinking that it was like walking parallel paths of conversation listening for common words that would allow our thoughts to intersect.*
>
> *We are more than memories, more than accomplishments and careers. We are more than time. Disease, I think, cannot destroy spirit. It is indestructible. It is all we are, and it stays with those we love and who love us.*

The moment the first exhibit visitor wrote the first comment, the space evolved organically. The conversations that occurred between the artists and the audience signalled community engagement. There was so much appreciation of caregiving as a work of art:

> *Music made material—how wonderful. Thank you so much for sharing your story this way.*
>
> *Thank you for sharing your creativity. I know artistic creativity can save one's life.*
> *A beautiful and thought-provoking project that so evocatively tells your story.*

The audience appreciated the creativity of the caregivers but also recognized their efforts to help their family member feel loved:

> *I truly love this work of yours. I loved peeking under the curtains and into your life experience. It is such a tender sweet piece of art that expresses love and respect.*
>
> *Such love in this! Truly inspiring.*

Through my photographer's eyes, I was able to include high-quality images to recreate some of exhibit space. The photographs also allowed me to see moments where I was not present. These photographs revealed an entirely separate layer of impact from the exhibit. The photographer, Hillary Winter, knew my intentions for the photographs and the exhibit but did not know the people attending. Winter's images revealed conversations between people that without the photographs, I would not have known existed. These moments became visible when I received the photographs that documented the event. These moments strengthen the impact of this research and its capacity to generate in-depth knowledge but also in-depth experiences with caregiving narratives. Some of the photographs showed caregivers speaking to other caregivers or their family members. Other photographs showed caregivers engaging with other caregivers' projects (which before the exhibit they had not seen). There are photographs of caregivers looking at their project after having been away from it for many months. Beyond how they contribute to the significance of the exhibit, the photographs add to the aesthetic experience for those who were not there. The caregivers formed connections with other projects and other caregivers. These connections attended to the caregivers' need for visibility. Being able to present their story in their way created an opportunity for acknowledgment of their creativity and strength.

6.3.2.3 Self-Discovery and Pride

The exhibit provided a space where caregivers could communicate the extent of their role while being honoured for their strength and creativity. The usual spaces for caregivers to share with other caregivers often evoke sadness and comfort from others. Caregivers may usually only talk about the stressful or exhausting aspects of caregiving. The exhibit allowed caregivers to share their story and highlight moments where they felt proud, all the while not ignoring the more difficult feelings associated with their experiences. The exhibit also allowed caregivers to see other caregivers' strengths and creativity. They were able to recognize themselves amongst a community and feel their experience and skill validated. The caregivers were able to view their journey as a work of art and experience the recognition of their community:

> *Given my particular circumstance in managing an Alzheimer's patient and my caregiver role, I was anxious to gain insight into how others manage a similar role.*

> *I immensely enjoyed getting to meet others who willingly shared their story. Very interesting! Although our perspectives varied from how we were related to the loved one, yet we all shared a common thread- dealing with and watching a loved one fade.*
>
> *Most caregivers displayed an extremely positive attitude towards 'the hand they were dealt' and were, indeed, not reluctant to share their experiences with each other. This, alone, made the event rather significant for me. Typically, in the wider community, one faces apathy and a somewhat negative behaviour to those afflicted with this illness.*
>
> *Sharing this experience with others and viewing others' projects help me to view my experience as unique, but not isolated.*
>
> *Presenting the work, and even now reviewing it, brings a sense of humbleness. This is my life and my feelings. Yet, I am very proud of what I have created and feel fortunate to have had the opportunity to share it.*

The exhibit space was a collaboration, and even though the participants did not meet until that day, they were collaboratively building an exhibit in private spaces leading up to it. The caregivers were a part of a community that they had built before they walked into the exhibit. The space that brought people together with some everyday experiences but it also allowed the participants to see the unique creativity in each other.

6.3.3 For Research and Practice

The exhibit has much to contribute as a community and an academic space. A creative approach to sharing research with the community is engaging, allows additional meanings to evolve organically, and it communicates emotion and facilitates connection. The exhibit took the research "data" beyond sharing a story to being able to reflect on how people engaged with the data. Presenting caregiving as a work of art encouraged emotional connection. This was evident in the audience comments, which described their emotional response. The space that the exhibit created placed participants' voice parallel (if not above) that of the researchers. I intended the exhibit to give visibility to the caregiver/artist and to honour them as an expert in their story. Exhibit visitors appreciated the way the exhibit presented the themes in research, the involvement of the caregivers in sharing their contribution, and the learning space created.

6.3.3.1 The Care Journey

The implication of including the invisible spaces of care highlighted in this study is that we can begin to see family caregiving, not as individual tasks or transitions, but as a continuum of care sometimes visible and sometimes not. The literature on landscapes of care alludes to this continuum by acknowledging that physical closeness is not a defining factor of emotional proximity. If we delve a little deeper into the metaphor of "landscape", we can assume that beyond what we can see from a distance, there are many layers of activity happening beyond the scope of where we stand. I use the term space in this thesis to address that caring for a family member with dementia is continual. Baumbusch & Phinney (2014) highlight "…family care work could be an integral component of philosophies that shape care in this setting, this remains a challenge because their involvement is often rendered invisible, and, as an under-researched area, it remains poorly understood" (p. 91). The invisible spaces of care help us to understand that caregiving continues between and through transitions and while adding in paid care or long-term care may free physical care space, the emotional connection continues.

6.3.3.2 Perceptions of Dementia and Caregiving

This study’s findings also expand societal perceptions of dementia. In Chapter 2, I stated that stigma is a reality for those living with dementia and their families. Discussions of dementia often use language like “diminished” or “deteriorating”. These perceptions can have a negative effect on caregivers. Lopez, Rose, Kenney, Sanborn & Davis (2019) found that the shame family caregivers feel leads to further isolation. When caregivers experience isolation, it negatively affects their quality of life (Greenwood, Mezey & Smith, 2019; van der Sanden, Stutterheim, Pryor, Kok, Bos, 2014). Quinn, Ress Jones, and Clare (2017) suggest that “…caregivers’ understanding of dementia can influence how they respond to the person” (p.533). These authors also say that “Stigma also affects the language/terminology used by caregivers. They may refer to symptoms rather than diagnosis, especially with the individual, which normalizes their experience but diminishes the severity or significance of support needed” (p.558). Part of this study’s contribution is that it adds visibility to both the caregiver and individual with dementia’s narrative. In making family caregivers’ love and creativity visible, I am also saying that they and their loved one living with dementia are deserving of love and creativity. An arts-informed lens provides a chance to find deeper meanings through creative expression, but also as Leavy (2015) suggests, it is an opportunity to counter stereotypes and include stories not always heard. Positive perceptions of dementia can have a positive impact on how providing care and those receiving care experience their daily lives and the narratives that define them.

6.3.3.3 Creative Research Contexts

Another impact of this research is the validation of creative and flexible space in qualitative research. This research engaged the caregivers' stories as a tangible expression of their narrative so a multidisciplinary audience could find connection. This expression does not require the caregiver to re-tell their story repeatedly to different audiences but allows an expression they are proud of to travel carrying their voice with it. Sharing one's experience can be exhausting and emotional. In the exhibit space, the caregiver stands beside their story with pride and allows the text to do the telling.

The text includes written materials in the room, but it also includes the room's contents and anticipating the viewer's experience. Intention fills the space but how the viewer derives meanings varies according to their connection with each individual and the themes within their projects. Cole and McIntyre (2007) refer to this kind of research as having an "ambiguous nature" (p. 312). They suggest that through this ambiguity, they can "…engage the audience in experiencing and attaching meaning to what is presented" (p. 312). The potential of the exhibit to add rich and in-depth knowledge to a field is reliant on the multiple meanings permitted. The exhibit experience provides the audience with multiple texts to engage. The texts in this space include the materials, and multiple meanings caregivers chose to share.

Chapter 7
Reflections

This study is the story of mothers and fathers, husbands and wives, sons, and daughters, people who have a relationship with a loved one living with dementia; caregivers; artists. In this research, being an artist means being able to wear different hats, take walks that have no direction, tear down walls, sing without notes, allow the elements to change the shapes, take the risk of being seen but not heard, peer through a window with an obstructed view, find permanence in unusual places, and piece together a puzzle with no end picture.

To my knowledge, this is the first study to explore the potential of arts-informed methods to engage family members' creativity in their everyday lives caring for a loved one living with dementia. In doing so, this study illuminates often-invisible creative aspects of the role. Care demands may have an impact on one's capacity for creativity, but it is still present. The participants in this study demonstrated rich and creative thinking in providing care for a loved one in dementia and in the process of sharing their experience through image, sound, object, and text. Participants used the creative project to draw out their strengths and share them with others. Presenting various themes through symbol, imagery, and metaphor encouraged others to connect with the emotional and practical components in their stories. In their study of viewing art as an intervention for caregivers, Roberts, Camic, and Springham (2011) discuss how the community setting encourages social inclusion and also helps to reduce the impact of stigma.

The creative projects communicate a great deal on their own, and the participants' creativity continues to provide a site for connection and understanding in the form of this thesis.

Connection is the most significant contribution of this research. Caregivers were able to connect to their creativity and know their strengths as valuable to others. Connection with others in the exhibit space bridged an academic and community audience. There was also a bridge between caregivers, which does not usually happen outside of a support group environment. I observed connection through creativity at every point in the study, beginning with myself and each caregiver in our initial interview. When I began this research, I expected to see caregiving as a work of art because I asked participants to produce a creative project. I hoped that through creative projects I would learn more about the emotion involved in caring for a loved one living with dementia. Roberts, Camic and Springham (2011) found that "…art-viewing in a group within a gallery setting has the potential to be used more widely as a community-based, low-cost and non-clinical activity to provide social and psychological support for carers of people with mental-health problems" (p.1). The creativity used to create arts-informed research products would be matched by the creativity in their everyday care role and that this creativity would illuminate aspects of their lives that they could not articulate fully with words.

The participants' individual and collective contributions lift invisible caregiving spaces and consequently expand our definition of everyday caregiving as an emotionally dedicated space that requires creativity. This is a significant finding. Creativity is required from caregivers but also supports them and their loved one. The potential here is incredible. If there is support for caregiver creativity there is reciprocal support for resilience. McFadden and Basting (2010) suggest that “people demonstrate resilience through their acts of creativity. In addition, the opportunity to express oneself through creativity can promote a sense of control and strengthen social ties, thus supporting resilience” (p.150). By continuing to explore and understand how caregivers engage creativity, we can better understand how to support their strengths in earlier stages and across the trajectory of caring for a loved one with dementia.

The findings in this study reflect visibility with multiple layers. The participants experienced elements of self-discovery, where they saw their creativity. The exhibit pieces made their experiences visible to the community and family and friends. This thesis adds an essential layer of visibility to the caregiving role and builds on current literature on family members caring for a loved one living with dementia. Jansson (2001) states that observational studies allow researchers to get closer to the everyday experiences of caregivers and that this helps illuminate invisible aspects of care (p. 809). My study builds on this by demonstrating how there are aspects of caregiving that only the caregiver can access (unobservable to a researcher) within their relationship and it requires a method that allows for creativity and reflection. These aspects are not observed until the caregiver can know them because they are changes from previous circumstance, or adaptations to regular routines, or slight creative movements over long periods.

Using a creative lens provides an opportunity for transformation. This transformation occurs when participants can discover and share their strengths with others. Creativity is transformative at several levels. First, a creative lens encourages people to connect with their experience in a way that is meaningful to them. Creative engagement can also have a positive effect on health and well-being (Stuckley & Nobel, 2010). In this study, caregivers transformed their experience into a creative project that showed that the act of caregiving is more than a daily list of tasks but a journey imbued with attention to their family member's need to feel loved; an effort requiring creativity at every level and across changing contexts. Through using arts-informed methods the caregiving experience allowed others to view otherwise invisible spaces of care. The people who came to the exhibit connected to the emotions expressed through symbol and metaphor, and it transformed their understanding of caregiving and dementia as well. This was evident in conversation with and in notes left for participants.

Through this study, we can understand the value of a strengths-based framework when looking at the caregiving role. An emphasis on the impact of caring on health and well-being is essential, but it informs strategies to provide relief or respite for caregivers. The current study highlights that caregivers require support for the person-centred care they provide and specifically for their creativity. Creativity frames experience and knowledge as a strength but also as precisely what their loved one with dementia needs. As McIntyre (2003) suggests, the caregiver is not a victim, but a person who experiences "tremendous learning and growth" and there is much potential to supporting the time a family member has put into their role. There is research exploring how personhood could guide family members (O'Connor, 2007). There is a need to look at the reciprocal value of what family members can offer to how we understand personhood. This work and current literature demonstrates that attending to a person’s need to feel loved requires creativity but that it arises out of an in-depth knowledge of the person. This study contributes to a need Kitwood (1997) identified to look “…beyond what is said to consider how personhood is embodied” (p. 126). This study found that recognizing how personhood is embodied relies on creative thinking and creative engagement. Creative response to a person with dementia’s core needs is required to provide care that attends to personhood.

A limitation of this study is that with a small number of participants I could not look at how demographics affect visibility or creativity in the caregiving journey (i.e., health, physical ability, financial capacity, social support, rurality, etc.). While it was not within the scope of this study, I can see how a further exploration of these factors would contribute even further visibility to the familial dementia care role. While I was able to present pieces from each narrative, they were not generalizable findings about one specific demographic. There is still more research to do. Although I acknowledge that gender plays a role in how caregivers shift responsibilities from the relationship’s previous arrangement, this study did not look at how men and women experience the role differently. Another limitation is that although rural caregivers were included, this study did not zero in on the impact of caring in a rural context. One thing this study can say about these elements is that familial dementia care has invisible spaces and for those affected by reversed gender roles and those living in communities that are more rural, face further invisibility. There is a need for further research to explore the factors that compound invisibility for family members providing dementia care. As society develops supports for family caregivers, it is important to support their strengths rather than only providing time away once they are exhausted in their role. A focus on creativity as a supportive mechanism would, however, support caregivers at every stage of caring, including after the loss of their loved one. Based on the experiences of those in this study, creativity was able to bring inspiration to those just starting the care journey, support to those dealing with the middle to end stages of dementia and comfort and pride to those who had lost their loved one through the recognition of how rich the care they provided was in retrospect.

This study captured family caregivers' experiences of caring for a loved one living with dementia through text, symbol and metaphor, and imagery. We heard from family members who invited us into their story. We learned and saw what that care looks like and how it extends into spaces requiring emotional and physical presence that are often invisible to those outside of the relationship. We walked through an exhibit that illuminated these care spaces through song-writing, singing, home renovation, photography, painting, poetry, short story, film, pencil-sketch, geo-caching, felted-wool, digital story, mixed media, and play-dough. We connected to these pieces through the caregivers' interactions with metaphor/symbol, imagery and the physical presence of a person living with dementia. Most importantly, we paid tribute to family members creatively caring for a loved one living with dementia.

This study emerged from a recognized gap in understanding the family caregiving role and creativity's place within it. In order to demonstrate the value of creativity as a caregiving skill, this study expands the scope by making invisible spaces of care visible.

This study contributes to caregiving knowledge by demonstrating that there are aspects of family caregiving that remain unseen and that a creative lens can help researchers make those aspects visible. By looking at caregiving with a creative lens and by using a methodology that honours the value of connection in creative methods, the participants in this study came to know, share and value their creativity as an incredible strength in caring for a loved one with dementia.

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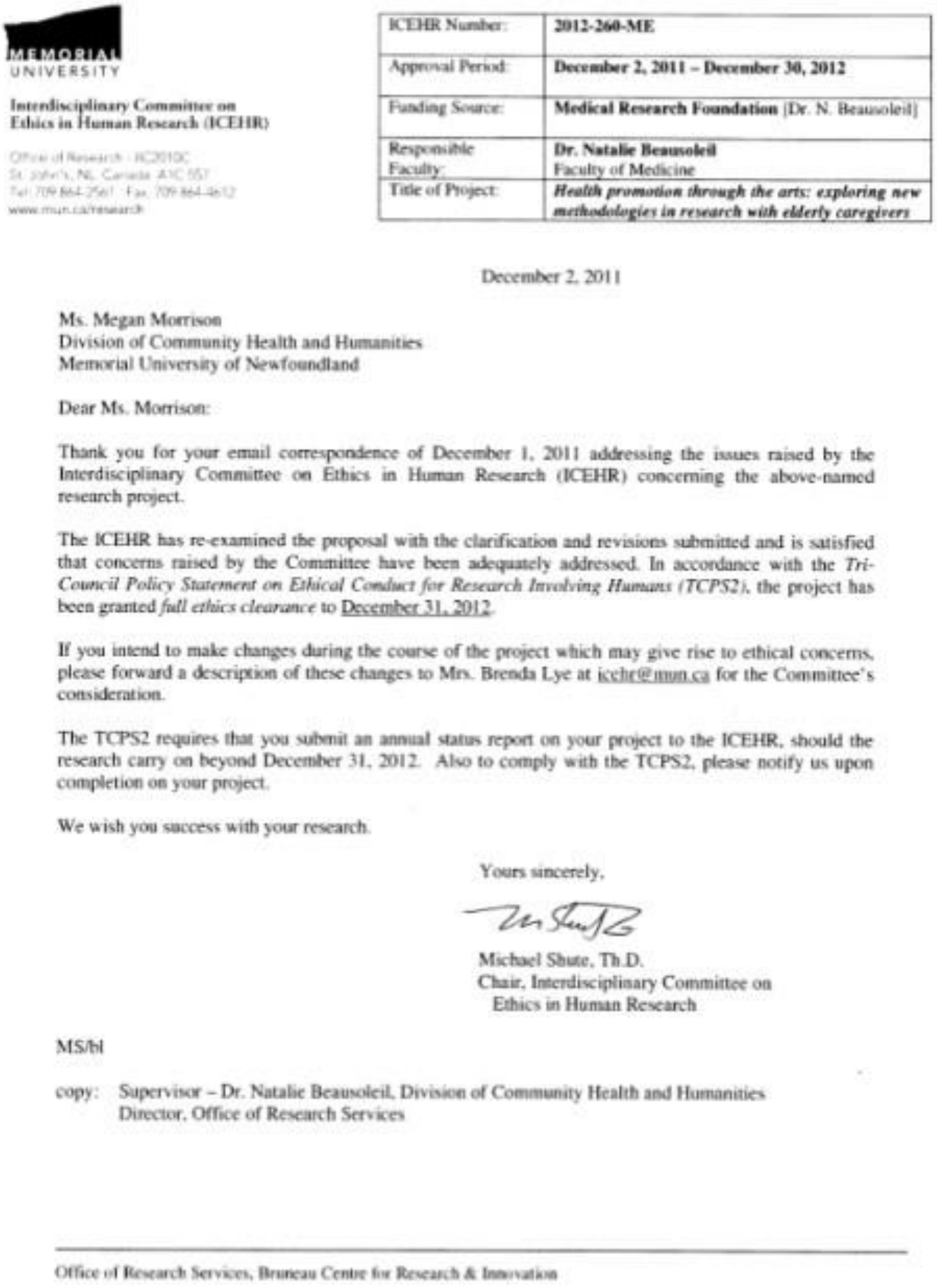
Appendix A Ethics Approval Letter



MEMORIAL
UNIVERSITY

**Interdisciplinary Committee on
Ethics in Human Research (ICEHR)**

Office of Research · IIC2010C
St. John's, NL Canada A1C 5S7
Tel: 709 864-2561 · Fax: 709 864-4612
www.mun.ca/research

ICEHR Number:	**2012-260-ME**
Approval Period:	**December 2, 2011 – December 30, 2012**
Funding Source:	**Medical Research Foundation** [Dr. N. Beausoleil]
Responsible Faculty:	**Dr. Natalie Beausoleil** Faculty of Medicine
Title of Project:	***Health promotion through the arts: exploring new methodologies in research with elderly caregivers***

December 2, 2011

Ms. Megan Morrison
Division of Community Health and Humanities
Memorial University of Newfoundland

Dear Ms. Morrison:

Thank you for your email correspondence of December 1, 2011 addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) concerning the above-named research project.

The ICEHR has re-examined the proposal with the clarification and revisions submitted and is satisfied that concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, the project has been granted *full ethics clearance* to December 31, 2012.

If you intend to make changes during the course of the project which may give rise to ethical concerns, please forward a description of these changes to Mrs. Brenda Lye at icehr@mun.ca for the Committee's consideration.

The TCPS2 requires that you submit an annual status report on your project to the ICEHR, should the research carry on beyond December 31, 2012. Also to comply with the TCPS2, please notify us upon completion on your project.

We wish you success with your research.

Yours sincerely,

Michael Shute, Th.D.
Chair, Interdisciplinary Committee on
Ethics in Human Research

MS/bl

copy: Supervisor – Dr. Natalie Beausoleil, Division of Community Health and Humanities
Director, Office of Research Services

Appendix B Initial Meeting Question Guide

Caregiving and Dementia

Tell me about dementia…

Tell me about being a caregiver…

How do you and your partner relate to each other?

Tell me about some changes or transitions you have experienced?

Support

What do you do to relax by yourself or with your partner?

What are your sources of social support?

Do you have a hobby?

Creativity

What does the word creativity mean to you?

What parts of caregiving require you to be creative?

Arts

Tell me about times when arts have been a part of your life… What does it mean to be an artist?

Is there anything that you have not had a chance to talk about that you would like to share about your caregiving experience?

Appendix C Creativity Cue

	Hobby	Interest	Sell/Show	Group	"I'm not good at it"	No interest
Carpentry						
Quilting						
Collage						
Painting						
Drawing						
Writing						
Singing						
Instrument						
Stencils						
Crochet						
Knitting						
Embroidery						
Building						
Stained Glass						
Card Making						
Sewing						
Cooking						
Baking						
Acting						
Metal Work						
Chorale						
Dance						
Comedy						

Other ___________ **Other ___________**						

Appendix D Informed Consent Form

Title:	**Seeing Caregiving Through (a Creative Lens): Families share their stories of caring for a family member living with dementia.**
Researcher(s)	Megan Morrison, Memorial University of Newfoundland,

You are invited to take part in a research project entitled:
"**Seeing Caregiving Through (A Creative Lens): Families share their stories of caring for a family member living with Dementia.**

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Megan Morrison, if you have any questions about the study or for more information not included here before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Introduction

I am a PhD student in Community Health & Humanities, which is in the faculty of Medicine at Memorial University of Newfoundland. I am looking for ways to be creative in my approach to research and research participants and more specifically to finding ways of supporting caregivers. I am interested in art and music. I sing and write blues music, play the piano and I like to paint. I also have a sewing machine. I am interested in the impact that art and music can have on healthy and positive experiences of aging. I am also the granddaughter of someone with dementia. I have done research before where persons with dementia were the main participants. When I spoke with their caregiver loved-ones, I heard a lot of different things. Some told me love stories. Some had creative forms of communicating and others were struggling and very tired. Because of their strength, I became interested in ways of making life more enjoyable for caregivers *with* their family members. I seek to find a way to strengthen the tools caregivers already have and improve their capacity to cope and even enjoy their relationship with their family members.

This project looks at ways of improving the health and well-being of older caregivers of persons with dementia. The main idea is that creativity is something we use in our day to day life even though not everyone believes they are creative. The arts are one way that people recognize their own creativity. This project is aimed at giving you the opportunity to recognize your own creativity, share your experiences, and develop new skills and possibly new community connections. It is my hope that through developing confidence in an artistic setting, you will feel more confident in the situations you come across at home.

My research question is: in the context of caregivers of family members with dementia, what is the impact of creative activity on individual health/well-being, confidence in their caregiver role and experience of creativity within their relationship?

Purpose of study:

This study brings caregivers with persons with dementia together to participate in creative projects with three purposes:

a. To increase individual caregiver confidence in being creative
b. To demonstrate the value of creativity as informal support for caregivers
c. To share the knowledge and experience of caregivers with the community through art.

What you will do in this study:

What is involved in participating?

First, an initial interview will be scheduled at a time of mutual convenience. This can be in your own home or at an agreed meeting place. To ensure that I can recall your input accurately, I will use a small recorder to tape our interview. This recording will not be shared with anyone except for myself and my supervisor. The interview will not be formal and you will be given the questions ahead of time and you are invited to bring notes. I will ask you to talk about your experience of being a caregiver and your perspective of what creativity means. The interview will end with a creativity inventory and I will ask you to rate your interest in each activity. At this point I will give you a journal. In this journal I ask you to write any thoughts related to creativity, communication, caregiving or dementia. You can write, draw, doodle, paste….whatever you like. The journals will be collected at the end of the project and if you wish, you may talk about what is included in yours.

> **Second,** the researcher will meet with you a second time to discuss a creative arts project. This project will give you an opportunity to share your caregiving story. All materials required for your participation will be provided to you free of charge, including tea/coffee and a snack, and taxi cab transportation as well as respite care (if you require it). There are no costs associated with participation. The final component of this research is to exhibit your creative project and others at a community research exhibit in St. John's Newfoundland.

Length of time:
The study will last six months. You will be expected to participate in one interview and a second meeting and as well you will be given the option of attending the exhibit. *snack and coffee included in all participant activities

Withdrawal from the study:
Your participation is voluntary and because of this, you may withdraw at any time with no consequence. Should you decide to withdraw from the study, it is your decision as to whether you want the data collected up until that point to be used. For example, if you have completed the interview but cannot attend the final workshop, we would still value the ideas you shared, however if you do not want us to use them, we will not.

Should you decide to withdraw from the study, you are not required to give a reason and no explanation will be asked of you.

Possible benefits:
It is not known whether this study will benefit you.

A few possible benefits are:

- Developing new connections within the community
- Learning new skills and enjoying creative arts activities
- The opportunity to share your knowledge and experience with others.

Possible risks:
Talking about caregiving and dementia can be upsetting at times. There are supportive services through the Alzheimer's Society and the Seniors Resource Centre of Newfoundland and Labrador, whose contact information will be available to you. Should you need a moment to yourself during one of the workshops, there will be a separate space to sit for a break away.

Confidentiality vs. Anonymity
There is a difference between confidentiality and anonymity: Confidentiality is ensuring that identities of participants are accessible only to those authorized to have access. Anonymity is a result of not disclosing participant's identifying characteristics (such as name or description of physical appearance).

Confidentiality and Storage of Data:

a. All identifying information will be kept in a locked cabinet accessed only by Megan Morrison and her supervisor. Any information kept on the computer will be password protected. The data collected from the initial interviews will be kept confidential. You will not be identified as having given an interview. Anonymity cannot be guaranteed during the workshops as some participants may share their real name with other participants. The interview and the data will be kept separate until the time of analysis.

b. All data will be protected by lock and password. Myself (Megan Morrison) and my supervisor (Dr. Natalie Beausoleil) will be the only persons with access to identifying information. The data will be kept for five years for analysis purposes and will be deleted and shredded after this time.

Anonymity:
As the principle investigator I will make ever reasonable effort to assure your anonymity. I will not identify you in any report or publication unless I have your explicit permission.

Recording of Data:

During the interview I will have a small voice recorder turned on. This is used to make sure that I remember your ideas correctly and you are not misrepresented. If during the exhibit I wish to take a photo of you or your art-piece, I will ask you directly for permission and provide you with an additional form to sign.

Reporting of Results:
The data collected during this project will be shared in my PhD dissertation and in presentations of my research through journal publications and at conferences. Your individual art-work may be photographed in order to accompany written reports. You will be asked for permission before photos are taken. The physical products you create may be shared with the greater community, however this is also your decision. Should you decide to keep your art-work and/or not share it, there is no negative consequence in doing so.

Sharing of Results with Participants:

It is important that you are a part of the research decisions that are made. After our interview, you have the opportunity to review the transcription of your words. If you want to make a change or omit something that you said during the interview, it will be changed or omitted without negative consequence. I want each participant to feel that they have shared their experience and knowledge in a way that they are confident about.

Questions:

You are welcome to ask questions at any time during your participation in this research. If you would like more information about this study, please contact: Megan Morrison 709 727-3096 m.morrison@mun.ca or you may also contact my supervisor Dr. Natalie Beausoleil 709 777-8483 Natalie.Beausoleil@med.mun.ca

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.
- You have been able to ask questions about this study.
- You are satisfied with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to withdraw from the study at any time, without having to give a reason, and that doing so will not affect you now or in the future.
- You understand that any data collected from you up to the point of your withdrawal will be destroyed if requested.

If you sign this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your signature:

I have read and understood what this study is about and appreciate the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

☐ I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation at any time.

☐ I agree to be audio-recorded during the interview and workshop

A copy of this Informed Consent Form has been given to me for my records.

______________________________________ __________________________________

Signature of participant Date

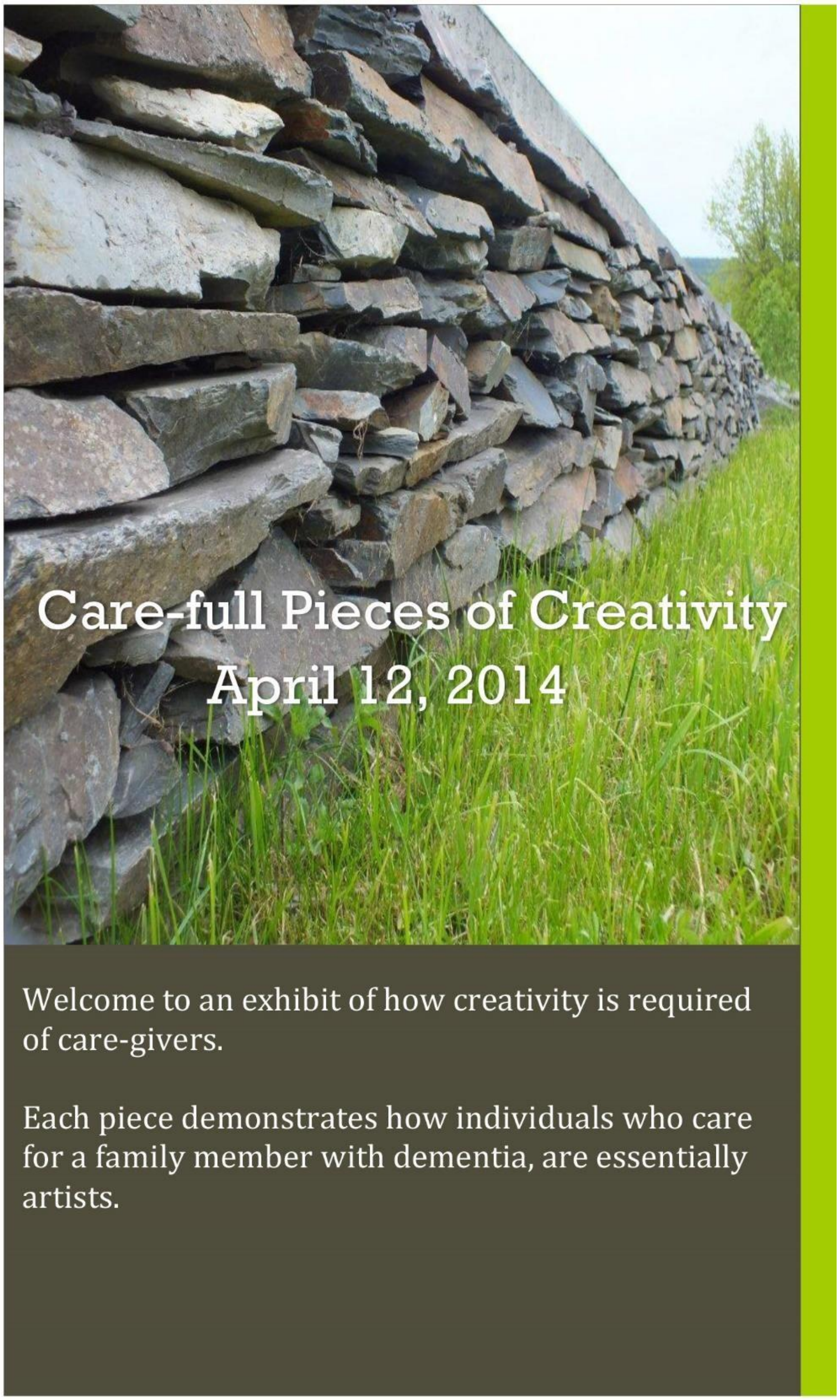
Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

__________________________________ ________________________________ Signature of Principal

Investigator Date

Appendix E Exhibit Program



Care-full Pieces of Creativity

April 12, 2014

Welcome to an exhibit of how creativity is required of care-givers.

Each piece demonstrates how individuals who care for a family member with dementia, are essentially artists.

Thank you…

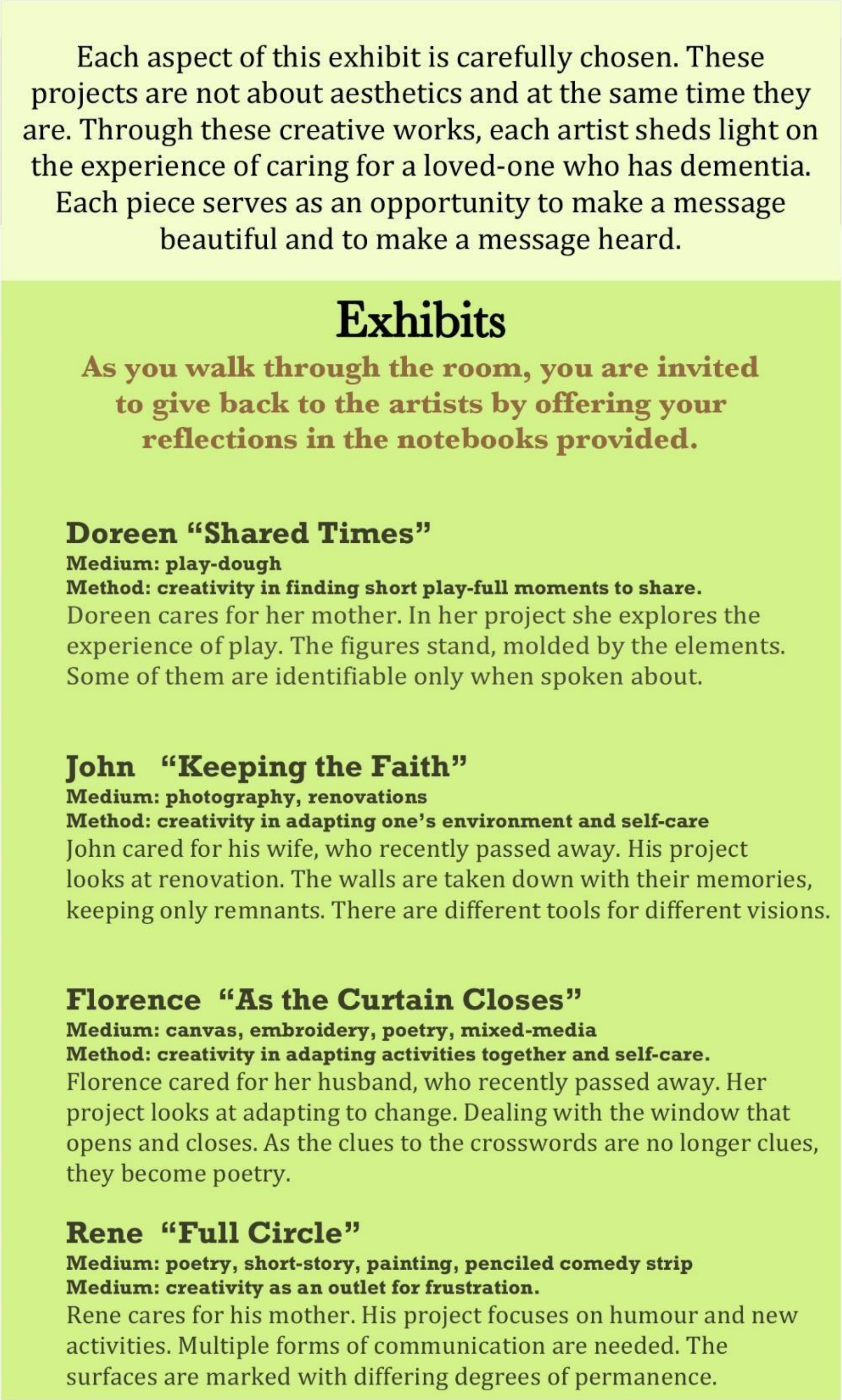
Care-givers and their families. Dr. Natalie Beausoleil (PhD supervisor). Dr. Victor Maddalena, Dr. Gail Wideman, Dr. Ardra Cole (Supervisory Committee). Kyle McDavid. The Seniors Resource Centre, The Alzheimer's Society of NL, Reid Music, Best Kind Design, Eastern Medical Supplies.

About the Exhibit:

Care-givers of a family member with dementia were asked to participate in a research interview, collaborate with the researcher on a creative project idea, and complete a piece that accomplishes a minimum of two goals. First, to make beauty out of a piece of their experience with care-giving. And second, to share the creativity that is required in caring for someone living with dementia, with the community.

This exhibit is the final piece of arts-informed research study conducted by Megan Morrison. She is currently a PhD Candidate in the division of Community Health & Humanities in the Faculty of Medicine at MUN.

Please contact her with any questions or feedback:
(709) 727-3096 -or- m.morrison@mun.ca



Each aspect of this exhibit is carefully chosen. These projects are not about aesthetics and at the same time they are. Through these creative works, each artist sheds light on the experience of caring for a loved-one who has dementia. Each piece serves as an opportunity to make a message beautiful and to make a message heard.

Exhibits

As you walk through the room, you are invited to give back to the artists by offering your reflections in the notebooks provided.

Doreen “Shared Times”

Medium: play-dough
Method: creativity in finding short play-full moments to share.
Doreen cares for her mother. In her project she explores the experience of play. The figures stand, molded by the elements. Some of them are identifiable only when spoken about.

John “Keeping the Faith”

Medium: photography, renovations
Method: creativity in adapting one’s environment and self-care
John cared for his wife, who recently passed away. His project looks at renovation. The walls are taken down with their memories, keeping only remnants. There are different tools for different visions.

Florence “As the Curtain Closes”

Medium: canvas, embroidery, poetry, mixed-media
Method: creativity in adapting activities together and self-care.
Florence cared for her husband, who recently passed away. Her project looks at adapting to change. Dealing with the window that opens and closes. As the clues to the crosswords are no longer clues, they become poetry.

Rene “Full Circle”

Medium: poetry, short-story, painting, penciled comedy strip
Medium: creativity as an outlet for frustration.
Rene cares for his mother. His project focuses on humour and new activities. Multiple forms of communication are needed. The surfaces are marked with differing degrees of permanence.

Glenda “Things are Changing”

Medium: song-writing, singing, slideshow.
Method: creativity in expressing loving memories.

Glenda cares for her mother. Her project captures the product of vulnerability and role reversal. A tune that has always held the same song, springs forth different and yet important lyrics.

Gerry “Carol’s Project”

Medium: geocaching, photography, video
Method: creativity in enjoying activities together.

Gerry cares for his wife. His project is centered on preparation for a journey with some surprises. A hidden treasure, where the path to find it is more important than what awaits at the end.

Mary “Oh Moon”

Medium: photography, projection slides
Method: creativity in taking rests with music and baking.

Mary cares for her husband. Her project looks at what filters moments. When the moon is full, the memories are darkened by its light. A recipe for a song that leads to a moment to one’s self.

Jeff “A Legacy of Love, Laughter, and Live Music”

Medium: poetry
Method: creativity in allowing music to bring joy throughout life’s transitions.

Jeff cared for his mother. His project states the importance of love over a lifetime. Pushing forward from note to note. The instrument may be worn but the music is written permanently.

Helen “I am my hat”

Medium: wool felted hats.
Method: creativity in expressing strength and maintain feelings of self-worth

Helen cared for her mother as well as two other family members. Her project looks at valuing one’s self. Creative outlets maintain the capacity to care for each kind of day.

The lives of families affected by dementia change quickly.
There are candles lit for those care-giver’s whose loved
ones have passed since their project began.