

**WHAT IS GRIEF AND WHAT CAN IT TEACH US?**

Sandra Dill,

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LORNE ELLSWORTH HALL  
January 22, 1917 - December 20, 1996

THE HALL FAMILY



Murray

Lisa

Me

Jane

Donald

Dad (Lorne)

Mom (Amy)

Final reunion - August 1996

## Dedication

For my mother, my brothers and sisters,  
and in the memory of my father,  
Lorne Ellsworth Hall who died in December, 1996

He was the center of my universe. His love and wisdom  
guided me. His music soothed me and his laughter  
replenished my spirit.

It were a salutary thing for each of us  
to work out his idea of death in the  
light of his days and the strength of  
his intelligence and to stand by it.  
Maeterlinck (1993) (cited in Nearing 1995, p. 68)

## Abstract

While a growing body of grief research focuses on how death affects the lives and the mental well-being of survivors, death continues to be a mystery and the ultimate human crisis. Grief is now emerging as a concept of increasing significance for health care professionals and it is influencing the care doctors and nurses provide for dying patients and their families. A narrative inquiry format supports this phenomenological study of death and dying from the dual perspectives of the author's professional death experience as a nurse and her personal grief experience as a daughter. Following the death of the researcher's elderly father, the author examined grief and considered the grieving process from a phenomenological perspective which extends the scope of the stages of grief (Kübler-Ross, 1969) that are the most familiar to health care professionals. The narrative inquiry emphasizes the interrelatedness of various aspects associated with grief, including knowledge, advocacy, autonomy, support, and spirituality. The study articulates the connections between these aspects on professional and personal levels. The author also discusses trends that are influencing the increasing need for greater understanding of the care of the dying and the ability of the family and health care professionals to respond. Although the family retains an important role in end-of-life-care, in the decades ahead some of their responsibilities may shift to a more formal involvement that will influence the grieving process of the survivors. Within the phenomenological framework of the researcher's death and dying experience, the author presents information, options, and coping strategies for those involved in such experiences.

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My Father

He shared with me his love, wisdom, joy of life, and his desire to die, peacefully. Our unique and loving relationship enriched my life.

Your own words guided your medical care even when you could no longer speak. You let your choices be known through your family. I honour you with this story. I will cherish the lessons you taught me in your life and in your death. I will always love you.

### The Genesis of the Inquiry

Prior to experiencing the death of my own father, I thought I knew about grief. Supported by my years of working as a registered nurse in long term care and in teaching palliative care students about death and dying, I felt a sense of confidence when I spoke about the events associated with the loss of a loved one. I spent my entire nursing career working in a nursing home environment where death was often the assumed expectation for my elderly patients. I became familiar with death.

Over the years, I became quite competent in my own ability to discuss grief as it was described in the research of Kubler-Ross (1969). I felt comfortable as a volunteer in a palliative care unit where I used my grief knowledge to assist and support families who sat at the bedside of a dying family member or friend. But in my understanding of dying, I had a tendency to generalize loss and this limited my understanding of the unique nature of this human experience for each individual. Then, for almost a decade, I observed my father's life become affected by the steady, progressive deterioration of his health and I tried to imagine myself in the position of those grieving family members.

As my father's heart condition worsened and the medical attention he received focused more on providing comfort and symptom control rather than cure, I knew he had reached the terminal stage of his life. But despite knowing his death was inevitable, I still could not believe he could die. The thought of life without my father was unimaginable. The depth of grief that I anticipated I would feel with his death was intolerable. Unlike the support I had provided for others who grieved, I could only *imagine* feelings of total despair and hopelessness. From my perspective, I now understood why the research (Ball,

1997) notes that only two hundred years ago grief was officially regarded as a cause of death; for in my mind, I felt that I, too, would be unable to survive such a loss when it happened. As Shelley (1976) cautions “No matter what you’ve imagined before you’ve experienced the death of a parent, when it happens it is unique, overwhelming, elemental, and powerful. Death is the ultimate crisis, the continuing mystery” (p. 347).

When my father died, I experienced the tremendous sense of loss that I expected and for a period of time I felt an extreme sense of emptiness — a type of involuntary emotional numbness that forced me to struggle to regain even the smallest feeling of emotional self-control and stability. I felt vulnerable and careless at the same time. My interest and desire to care about anything disappeared. Grief fragmented my concentration and I felt confused. Slowly, I became aware of the powerful feelings of loss that grieving families and friends in the past expressed to me. Now I knew what they were describing.

Following my father’s death, I realized the difference between understanding dying from the phenomenological perspective of a daughter rather than from the intellectual perspective of a nurse. As a grieving daughter, I began to understand that phenomenology can only be accomplished by doing it (Van Manen, 1990). Unfortunately, it took the death of my father for me to begin to examine loss from the perspective of my own grieving. I became curious about what I thought and felt during my own time of loss. I also questioned why I considered my grief experience to be unique and if so, what had contributed to creating that uniqueness.

Not long after my father’s death, I realized that I was also feeling emotions that I neither anticipated or knew about. I was experiencing grief-related feelings that I never

heard discussed. Instead of feeling a sense of hopelessness that would have appeared reasonable to me in this situation, I felt hopeful. To further complicate matters this new feeling of hope was unlike any feeling I sensed in the past. I felt energized by an odd peacefulness. In referring to the way Dad died, I experienced a sense of accomplishment. This was a strange word to describe emotions associated with death, but the feeling of having achieved or at least done something well was present in my grief.

These strange emotions combined with my sense of loss were all unfamiliar to me. At no time in my nursing career had I encountered words such as accomplishment to describe grief and nor did I find this terminology in the death and dying literature. Even my close friends and colleagues looked concerned when I referred to my unique grief feelings. Few seemed to understand my experience and I, too, began to wonder what happened to cause this unexpected response to my father's death.

As a result of my background and interest in death and dying, I felt it necessary to reflect on my experience with my father's illness and death and to understand my personal grief response. Van Manen (1990) suggests that an individual cannot reflect on their lived experience while living through that experience. As an unknown author stated "The human heart does not stay away too long from that which hurt it most. There is a return journey to anguish that few of us are released from making."

It has now been almost three years since my Dad died. It has taken this time for me to be authentic about my loss and to write about my experience.

Crafting this narrative made it necessary to step back into the experience of my dad's death and reflect upon those events with a particular kind of distance (Hillman,

1994): My story has therefore become a phenomenological reflection that is retrospective rather than introspective. I have deepened my understanding of grief from my dual perspective of a nurse and daughter, and it my hope that I can assist others by sharing what I have learned from those difficult times.

Moving away from an emotional, yet still, personal recollection of my own experience to a more general reflection has placed the story of my father's death into an historical context. My narrative contributes to the grief education of others and provides an understanding of that which most take for granted about death and dying. My writing may also encourage health professionals and other families to examine the complex issues associated with dying, death, and grief from a broader perspective and to help such people recognize the critical need of continuing to understand and value dying and death as unique and important human experiences.

As I explored my own experience of understanding grief, it soon became clear to me that if understanding were perceived as an end in itself, then few would achieve complete understanding. Following from this, it would then be true that no one would be able to understand the grief experience of another. However, if understanding grief was perceived as a new way of viewing dying, then it should be possible for others who are not grieving to empathize with those who were.

When understanding is viewed phenomenologically, it is constituted in the difference between what it means to be a patient and what it means to be a nurse; what it means to be healthy and what it means to be ill. From this new perspective, understanding experiences and different meanings associated with illness, dying and death are identified.

For me, the writing of this thesis has been a personal experience that influences my life as a grieving daughter and my professional nursing interest in geriatric and palliative care. As a result of my dad's death, I am better able to understand illness, dying, and death as the complex human experiences that they are. The grief surrounding a death is complicated and cannot be characterized by the use of a singular description of grief. "What we must do is discover what lies at the ontological core of our being. So that in the words we find memories that paradoxically we never thought or felt before" (Van Manen, 1990, p. 13). My own grief experience, my grief memories, now influence how I discuss this often complex and misunderstood human experience.

My father and I shared a wonderful, unique and loving relationship. His death propelled me to reconsider some of my personal and professional beliefs concerning dying and death. During his lifetime, my father was my mentor and therefore it has not been unusual for me to recognize that even in death he has continued his counsel.

As a nurse I have always derived the most valuable lessons from my patients and their families. These teachers in my professional life have become teachers in my private life for the grieving process within my own family has been such a learning experience. The authenticity of my lived-experience of the grieving process is supported by Van Manen (1990) when he suggests that practice (*or life*) always comes first and that theory comes later as a result of reflection.

The grief of losing my father has been one of those life lessons. Dad's death changed my life forever and I wanted to pause, reflect, and relay what this experience taught me. I felt a sense of responsibility and empowerment as a nurse educator to share

my family's experience with other families. I needed the words to resonate off the pages and reflect in an authentic manner what my mother, my brothers and sisters, and I experienced.

As Goldberg (1989) states:

A synapse connected in my brain. I went home with the resolve to write what I knew, and to trust my own thoughts and feelings and to not look outside myself. I began to write about my family because nobody could say I was wrong. I knew them better than anyone else. (p. 2)

Writing what I knew to be true and trusting my own feelings and thoughts about the complex experiences centered around my father's chronic illness, dying and death was a true journey of unrelenting challenges. Before deciding on the question the methodology of the narrative was confirmed. From the beginning no other method of inquiry was considered. I needed the reader to be able to 'share' in my family's experience. I needed my writing to recapture the emotions of conversations, and the intensity of the feelings of everyone involved. I needed the words to bring back past events in a particular way that the essential aspects and the meaning of the experience were present. I needed the personal and private relevance of this humanistic experience to affect others.

The question demanded a phenomenological inquiry, anything less was unacceptable. It was not enough to place the recalled experiences in a narrative format. The purpose of a phenomenological study is to attempt to grasp the meaning of an already lived experience through reflection and interpretation. According to Van Manen (1990,



p. 11), by its nature phenomenological research is the study of lived or existential meanings; it attempts to describe and interpret these meanings to a certain degree of depth and richness. I needed the intersubjective, self-critical, explicit and systematic qualities of phenomenology to tell my family's story. As a nurse I had to step out of the security of my profession's tradition and authority of quantitative research and trust in the method and the truth of the holistic, humanistic qualitative model of the narrative. I had to stop thinking 'about' the story and learn to think 'with' the story (Frank, 1995).

As a grieving daughter I wanted the narrative to tell my family's story. As a nurse I recognized the contribution of the story to others, but as a nurse researcher I was awkward with the narrative. The method of inquiry was foreign to me. I was excited and fearful about the demands of phenomenological research and writing throughout the entire thesis process (and still am). The interpretive nature of the narrative challenged me with its complexity. The task of linking each human experience with interpretation as a nurse, daughter, sister, wife and researcher was relentless and exhausting. My personal involvement in the grieving experience of my family's loss provided a unique insight into grief that added authenticity to the study while at the same time was burdensome when my writing took me back into the lived events of Dad's death distracting me by the reawakening of emotions revealed in the vividness of words and meaning.

I never questioned the value of the story; I questioned my ability to present the lived-experience of my family in a manner that others could learn from their journey through illness, dying and death. When I spoke about this story I referred to it as 'my story'. My first challenge in writing this thesis was to believe in the authority of my own

words. I needed the story to be as authentic as the experience . . . . I needed to feel the connection of my family's grief experience and the texture of their names, images and emotions on the pages.

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## Chapter One: In the Beginning

### Theory to Practice: A Nurse's Journey

In my education as a nursing student, the phrases quality of care and quality of life worked their way into my professional vocabulary. Back then, my only understanding of death and grief was rooted in the earliest studies of Kübler-Ross (1969) who identified the emotional stages of grief as shock and denial, anger, bargaining, depression, and acceptance. For much of my professional life, the teachings of Kübler-Ross guided my caring for terminally ill patients and their families. Despite this theoretical framework for understanding death, I struggled to make sense of what I saw and what I felt as I witnessed their loss and grief.

During the three years of my basic nursing education, I observed many births and felt privileged to hear the tiny infants breathe their first breath and thus begin life outside the womb. I also sat at the bedside of dying, elderly patients as their lives moved toward death. Again, I felt privileged by what I witnessed. Throughout my nursing education, these experiences of birth and death occurred, yet never lost their impact nor their significance. My fascination for both never diminished but the more contact I had with dying patients and their grieving families, the more I became interested in learning how to provide well-informed, holistic (body-mind-spirit) nursing care to assist dying patients and their families through the transition from illness to peaceful death.

Fortunately, the mid 1970s witnessed the development of a more focused interest by health care professionals in the many complex issues involved in the care of elderly patients. Driven by the health care system's need to provide quality geriatric care to an

aging population, the issue of providing care to the dying elderly became part of an essential component of total patient care. Operators of long-term care facilities, including hospitals, recognized the value of providing this level of care to their dying patients and their families. The changes regarding “end of life care” (Goetschius, 1997, p. 43) began to occur.

As part of these developments in geriatric care came discussions of patient care focused on the specific issues of death and dying. Educational seminars and nursing journals provided opportunities for nurses to share their experiences with others, thereby gaining the knowledge and skills necessary to address the challenges presented by palliative care patients and their families. The chronic illnesses such as heart disease and vascular disorders that challenged health care since the 1930s (McCarron, 1991) were recognized as an area that required specialized medical consideration and treatment.

My position as a nurse provided a vantage point that separated my perception of the death experience from the patients and family members who I observed. My perspective of these events was similar to that of the *tourist gaze* where an observer watches events from a safe and comfortable place; I always carried the realization that I was an observer not a participant (Howes, 1991). The death experience was theirs and not mine. At best, I hoped to learn from those I watched so as to apply the new knowledge I acquired with grieving families I worked with in the future.

While I worked in geriatric nursing, caring for the needs of elderly strangers and their grieving families, my *own* family moved toward a similar health crisis. In parallel realities, I sat with my patient’s concerned family members and attempted to ease their

anxieties by explaining the medical jargon used to describe their loved one's diagnosis of Congestive Heart Failure (CHF). But I failed to see the irony of what was happening in my own life.

When I realized the seriousness of my father's failing heart, I internalized my sense of confidence in caring for other chronically ill patients into my personal understanding of what was happening to my own father. I believed that the transfer of knowledge and skills from my nursing experiences would be sufficient to support me in my own grieving process. As a nurse, I had the knowledge and the experience to anticipate what might happen to Dad with his heart condition. When my patients or their families were in crisis, I reacted with a sense of professional clarity. But now, the crisis involved my own loved ones and my ability to think and act clearly was compromised. As Dad's daughter, I could never be certain of my response. I was both nurse and daughter.

Through my nursing education and professional experience I was socialized into specific values and attitudes that characterize my professional role and identity (Fox, 1989). According to Fox, this professional socialization involves more than learning how to adjust to different situations. Becker (cited in Fox, 1989) suggests that the individual life patterns and personal identity of health professionals are broken down or dissocialized in order to build up new identities. Conversion and commitment to their enrollment in the professional community is enhanced by the intensity of the trials the trainee must endure. Professional conversion is achieved when new concepts, values and language are adopted and a moral transformation occurs affecting emotions, attitude, and behavior. Health

professionals educated in such a manner play their professional roles until they complete an unconscious process when they assume the new role of doctor, or as in my case, nurse.

My reality shifted. The boundaries crumbled between my training to think and respond as a nurse and yet feeling like a daughter. My two roles flowed into each other. My father was dying. No longer was I an observer. *My time had come to participate in the death experience and its resulting grief. This was now my grief, my loss, and my pain. These were no longer grieving strangers; this was my family at the bedside.*



## Chapter Two: God Grant Me the Serenity

### Personal Reflections - December 16, 1996: A Night of Terror

*"Your father had a stroke. He can't speak and he's paralyzed. He's not responding."*

Although I anticipated and dreaded receiving this phone call for what seemed like an eternity, the impact of what I heard was no less devastating. My brother-in-law's words sent me into an immediate crisis. All the weeks, months, and years of trying to prepare myself for this moment were useless. Nothing helped. I struggled to survive the terrible shock of this hopeless news and to make sense of what I just heard but I was drowning in my own terror.

My immediate response to the telephone call was from the heart of a daughter. I felt Dad's paralysis as if it was my own. I cried uncontrollably. I anguished over what the stroke did to his already frail body, his handsome face, his quick wit, and his wonderful gift of wisdom. My heart ached and I grieved the loss of the father I once had. I imagined the devastation of the stroke. It overwhelmed my thoughts.

Without warning, the words *your father had a stroke* trespassed into my own life. The defense mechanisms that supported me through difficult times were shattered. This was my father who was paralyzed and who couldn't speak. This was no longer one of my patients and I no longer felt like a nurse. If I had ever been protected by my professional objectivity, I was not now.

In the past, when I sat with my patients who suffered the devastating effects of a stroke, the bodily effects it left were unimportant to me. The physical changes in my

patients' appearance and their inability to remember faces or names of their loved ones were less important to me than the relationships that I shared with my patients. As their nurse, I was able to see the unaffected person behind the physical and emotional changes and I encouraged their grieving families to do the same. But, because of the phone call, everything changed.

My mind exploded with multiple flashing images of frail old men and women slumped sideways in motionless wheelchairs, with their lifeless, droopy arms cradled awkward against their boney chests. Their dimmed eyes pleading and searching endless hallways for a glimpse of a familiar face. These were professional images invading my personal life.

I felt like a liar. All the years I spent encouraging family members not my own, now felt distant and unreal. Somehow, I needed to find the strength and understanding that I saw in those other daughters. I needed to survive this unrelenting helplessness that terrified me. I felt that my father and my mother and my brothers and sisters needed to be cared for. I was overwhelmed by the 3000 miles that separated us and my own feeling of "desperate necessity" (Frank, 1995, p. 154). I needed to be home, to be with my dad, and to help my family. I needed to confront what frightened me most. I needed to *see* the stroke: to *witness* what it did to my father. I struggled using all my nursing methods which were most familiar to me to understand what was happening.

Like all nurses, I rely on my powers of observation to care for my patients and to make sense of my working environment. The ability to see the patient is fundamental to what nurses do and is a critical support to our other senses of smell, touch, hearing, taste,

and intuition. Together these are the basic, yet valued sensitive tools which health professionals use when gathering data about their patients and their families to assist nurses in assessing, implementing and evaluating care, and making treatment plans appropriate to their patient needs (Seidel, Ball, Dains & Benedict, 1991). Interpretation and the ability to make sense or to make a diagnosis relies on the information that by using their senses health professionals have accumulated about the patient's symptoms. Competence is necessary in relating professional observations to other health professionals to facilitate the correct diagnostic decisions and matching it with the most appropriate treatment is essential in the nursing field. My professional training made me realize that seeing my dad was critical for me.

Although the telephone message informed me that Dad could not speak and was paralyzed, I needed to see what was *not* being said. I needed to interpret what was happening to Dad in a way that not even my family's words could provide. I reacted like I did so many times before when I needed to understand what was happening in the lives of my patients; I thought like a nurse and searched through medical books for the information I needed so urgently to find.

Frantic, I tore through the stacks of my anatomy and physiology books flipping through page after page of information on *strokes*. I needed to know the type of brain damage that Dad suffered in order to better understand what was happening with him now and what his future might be if he survived. Miles away from my father's hospital room, I

tried to rely on my knowledge and my experiences in geriatric nursing to help myself understand.

Although I knew that a stroke or a cerebrovascular accident (CVA) was a common disease of the nervous system, I also knew that all strokes were not the same. Everything from the actual severity of the condition to the degree of paralysis that occurred, depended on where and how much of the brain was affected by the presence of a hemorrhage or a clot. The more extensive the damage, the more serious the consequences.

As I read through the medical causes and symptoms associated with a stroke, I understood what happened to Dad and the reality was overwhelming. As I started to piece together what the stroke meant for Dad, his quality of life, for his family, and for me, the words became hurtful.

Because my father was right handed and his speech centre was located on the left side (the now damaged part of his brain), I knew there would be a possibility he would never speak again, but it was also probable he would be unable to understand written or spoken words. He would have no bladder or bowel control and he would require total care with all his bodily functions. He would more than likely have personality changes accompanied by serious problems with intellect and judgement. He might not recognize the faces of his family.

Reading the textbook I felt like I was just given the only road map for a journey that my father, my mother, and our entire family had just begun. The information was like a terrible secret which I had to carry. What I knew set me apart from the people whom I

loved the most. My knowledge as a nurse gave me a perspective of what happened to Dad that was different from my mother, brothers, and sisters.

Being the nurse in a family is not an easy role. When a health crisis involves a loved one nurses cannot stop *feeling* like a daughter or son, but they do not stop *thinking* like a nurse. Nurses in a family are expected to provide ongoing medical information and interpretations of such information and support their family in a health crisis. They must be present as if on-call. However, these duties are not spontaneous nor can they be taken for granted.

Their degree of participation is often dependent on the nurses' interest and comfort in being involved in the health concerns of their loved one. Other factors include the ailing family member's understanding of their own everyday, or lay ideas and theories of health (Offer, 1989) and the degree of personal responsibility the ill person accepts in making his or her own medical care decisions. Patients who place their physician in the role of sole decision maker will be less likely to consider involving a family member nurse in their health care because it could be perceived as questioning the doctor's authority.

Patients who value making their own decisions about illness will consider and accept more easily the participation of the family member nurse in the maintenance of their health. Dad followed this philosophy of personal empowerment and involvement concerning his own health care. He encouraged my participation in assisting him with his health care decisions. My mother, brothers, and sisters appeared comforted by my being a nurse.

Whenever Dad experienced a new development in his health crisis the need for me to support my family escalated. Unfamiliarity with his most recent symptoms and treatments increased their sense of vulnerability. My family relied on my knowledge as a nurse to acquire the information they needed.

I am obligated to perform my nursing duties according to a Nursing Code of Ethics (1991) which guide me to provide information to patients in a sensitive, truthful, and understanding manner. I must proceed with an awareness of the interests, values, and needs of individual patients in providing all information. In addition, I also have the responsibility to assess the patients' understanding about their treatments and provide information and explanation that gives them the knowledge they require to respond.

Early in my nurse's training, I learned the critical importance of providing all information to patients and their families in a sensitive and caring manner. I developed my skills of observation and intuition to try to anticipate whether the information comforted them or caused them to become more upset.

The reality of my dual roles, *daughter and nurse*, became more intense as I read my textbooks. The description of a stroke in the familiar medical terminology complete with resulting implications concerned me beyond my perspective as a nurse. My nurse's knowledge of Dad's condition set me apart from my own family. I experienced the crisis of Dad's stroke from the dual perspective of being his daughter as well as a nurse.

I wondered how much my mother, brothers, and sisters already knew about what happened to Dad. I struggled to find a way to tell my family what I knew in order for each of them to participate in the decision making process that lay ahead.

Not all registered nurses choose to be involved in the health care of a family member. Some, albeit a small group, consider their involvement as a nurse in a health related family matter as too complicated. They become confused and frustrated at the loss of boundaries that separate the role of family member from the role of nurse. Many nurses who spoke with me about this issue stated that they never felt comfortable in the advocacy role that is often required of them as registered nurses. In the heightened emotional environment surrounding an ill family member, they wanted to relinquish their professional responsibilities to the other nursing staff. But for me, this was an option that I would never consider.

Although my books gave me a clinical description of Dad's stroke, the words could not give me what I needed most. I was still frantic to see him. The physical distance that separated Dad from me was my greatest obstacle. I was terrified that Dad would die before I got home. I could not imagine not being able to see him or care for him. I knew that if Dad died and I was unable to be with him that I would regret the absence for the rest of my life. The thought of living with that regret frightened me. I knew that when Dad died the grief would be all, if not more, than I could tolerate. I could not begin to imagine the guilt I would feel if I was absent when he died.

Rolland (1994) refers to this phenomena as the "willing" family care giver and he describes the serious negative consequences that can result when that individual is unable, for whatever reason to provide care to a sick or dying loved one.

In my professional life, I often spoke with distraught family members who made promises to provide care to a loved one and then were unable to do so. These people

appeared to suffer a great loss. Both men and women spoke about their deep sense of remorse not fulfilling the biblical commandment “to honour thy father and thy mother” (Harvey, Bond & Greenwood, 1991, p. 33).

Listening to these people, it was evident that unless something happened that made it possible for them to justify *not* caring for their loved one that this issue would burden them for many years. I did not want such a burden. My need to care for my father and to be with him when he died went beyond the notion that “care is a fundamental human imperative that must be obeyed” (Gordon, 1991, p. 45). I felt I needed to witness his dying in order for me to be able to feel certain that there was nothing more that could have or should have been done for him. I could not imagine the future burdened by a sense of self-doubt or thinking that I might have been able to help either my Dad or my family and that I failed to do so. I also knew that I had to care for my own grief needs.

All too often, the needs of individuals or families to care for themselves in crisis or for care themselves, are misunderstood or even overlooked. In the chaotic health care environment filled with intrusive procedures and fast paced time lines, the emotional needs of grieving loved ones can be overlooked. Family members may never be asked what they need in order to enable them to get through this experience of extreme stress and sense of loss.

In palliative care, I often hear nurses and social workers strive to do their best to meet the needs of the entire grieving family. Whenever possible, if a family makes a specific request, the staff provided meaningful suggestions based on their past experiences



with previous families. Some nurses share their personal grief self-care stories as an attempt to help others.

My self-care story was revealing itself. I felt that no one knew what I needed better than I did. I knew without a doubt that I needed to be home.

In the past, each of my brothers and sisters travelled home whenever Dad experienced a health emergency. During those times of crisis, we gathered together and became an intact family. We shared a sense of strength and comfort. We felt complete and there was no need to regret the absence of the other. We were comfortable in each other's company. We could express our emotions as siblings who would understand each others needs and behaviors.

I knew that someday the events of the final days of Dad's life and his death would become cherished family memories and that I needed to be with my family to share in those memories. Without being there to witness Dad's dying, I would be an outsider to my family's recollections, forever separate and apart from my mother, brothers, and sisters. I had a close relationship with my family and I wanted this closeness to remain the same, most important now, when Dad's death would change our lives so permanently. I wanted our father to know before he died that each of his children came home, to say our *final goodbyes* while he was still alive.

### Chapter Three: To Accept the Things I Cannot Change

#### Personal Reflections - December 17, 1996: Travelling Home

I wrote in my journal travelling all the way home to Nova Scotia. I wrote to isolate myself, to keep strangers and their meaninglessness prodding airport conversations away from me. Frantic, I wrote on every scrap of plain paper I could find. Words and phrases filled my head and seemed to be everywhere; I felt helpless to avoid them. My thinking was disjointed and haphazard as bits and pieces of fragmented thoughts passed from my brain onto the paper. I could not concentrate. Panic moved my fevered pen. I was irrational with the fear of losing my father.

I knew I was different from the rest of the Christmas travellers. The anguish of my grief isolated me from their seasonal joy. While others carried bundles of coloured wrapped gifts in their arms, I carried the weight of the world in my heart. The families of strangers smiled and laughed in anticipation of celebrating another Christmas with their loved ones, while miles away my mother, brothers, and sisters sat in a hospital room with Dad wondering if this would be their *last* Christmas together.

My thoughts were about my father. I had no feelings of festive joy, the celebration of Christmas seemed surreal and unimportant. My grief made me a foreigner to the holiday and erased all desire and interest in Christmas. Numb inside, I did not even resent my fellow traveller's outbursts of laughter. I felt trapped inside a vacuum or void where a strange absence of emotion separated me from everything and everyone. I struggled to find stability in the turmoil and chaos that surrounded my heart and spirit.

My nursing sensibility was the method of control over the feelings of hopelessness, loss, and uncertainty that overwhelmed me. I grasped at anything to help me through my panic. I challenged my feelings by focusing on what I knew to be true. Whether the truth was good or bad was not important as long as it stopped the uncertainty.

Dealing with uncertainty has never been a personal strength. When given the proverbial choice of first hearing the good news or the bad news, I chose the latter. I always preferred the certainty of knowing over the feeling of living with uncertainty and doubt even when I knew the information might be unpleasant. My discomfort with uncertainty was incorporated into my professional life. It became a crucial asset, that helped me to better understand this same need for certainty in patients and their families.

During my years of nursing, there were numerous occasions when patients or family members pleaded with me to explain what was happening or what they could expect to happen in the future. I found both as a nurse and a daughter that in the dealing with a health crisis the human need to regain some degree of control over the unknown was important.

Wright and Leahey (1984) associate this type of purposeful inquiry as a means to achieve psychological control, a problem-solving-method useful in unfamiliar, stressful situations. The medical information health professionals communicate, influences behavior and decision making and may lessen the stress experienced by some individuals during a crisis. While the seriousness of the situation remains unchanged, the level of uncertainty associated with the emergency is lessened.

For many patients and family members experiencing a health crisis having control over the unknown provides the sense of security they feel. As they become more informed, they tolerate more anxiety and appear less stressed. I, like others I witnessed, needed to find some control over my dad's uncertain situation. From my dual perspective as a daughter and a nurse, I reflected on what I knew of my father as a man and what I knew about the stroke he suffered.

As I travelled home, I recognized that my concerns were different from the rest of my family. I knew that my worries about Dad's stroke were influenced by my nurse's awareness and my experience in geriatrics. Though absent from him I already possessed some knowledge about Dad that my family did not have. Without seeing my father, as a nurse I started to put into place a logical plan to care for all of my family through this frightening and foreign experience. I knew that I would understand how I could help Dad when I saw him. Years of nursing other patients like my father would guide me.

Being a nurse, I have made very important decisions without being able to explain why. I selected choices based on a feeling that they were the right ones. Decision making by intuition (Cooper, 1997) is a skill that many nurses recognize and value because it helps them to provide high quality patient care.

Intuition is part of the practical knowledge that health care providers learn over years of performing a particular task. This practical knowledge is referred to as the know-how in the health care profession. The more nurses know about their patient's situation, the better their ability to use an intuitive sense. Several sources of information contribute to a nurse's intuition and decisions are never based on a single factor. Elements that

appear commonplace or unimportant may be essential to the final decision. Knowing what cannot be changed, such as permanent brain damage, is essential to any medical decision.

During my education and throughout my experience as a nurse, I realized how important it was for me to understand that medical care could not cure or fix everything. As uncomfortable as this fact was to accept, I understood the unavoidable irreversible physical and mental damage, or death. My awareness and acceptance of this reality was difficult when working with strangers, but with my father it was heartbreaking.

I am educated to examine and investigate illness events from a different perspective than non-health care professionals. This exploration often involves looking at the combination of events that may have led to a major health crisis rather than focusing on the crisis. Purposeful observation and objective methodical questioning are crucial to the success of this investigative process but this may appear to be rather cold and unfeeling when contrasted to the strong emotional needs of family members. When an ailing patient's family member is also a health care provider, the combination of these two distinct perspectives of objective and subjective needs can cause many uncomfortable, unnecessary additional family problems that would further complicate the crisis. In my experience as a nurse and a daughter, I needed to find a comfortable balance between finding the information I needed and doing so in a manner that avoided creating further anxiety for my family.

Now that I was with my Dad I needed to understand his behavior prior to experiencing this major stroke. I needed to link the previous details of those days, when I was absent, with the present. Like an investigator I was in search of that minute piece of

evidence that would make sense of what caused this *catastrophic* event. Without this combined insight my own fear would continue to cripple my ability to make decisions and to help others. I needed to hear my family's recollections of what happened and I had very little time to do so.

In brain injuries, time is critical, and realizing how Dad had already been compromised by several smaller previous strokes of trans ischemic attacks (T.I.A.s), the issue of time was paramount.

The recent stroke intensified Dad's existing health problems and the culminative effect from each of his past illnesses were overwhelming his weakened ability to survive. Dad was fighting the effects of this stroke but his life was being challenged by years of heart disease and the complicated interconnected health problems that plagued his life for the last twenty years. The longer Dad remained unresponsive, the greater the opportunity that even more lethal complications would occur, such as further strokes, pneumonia or failure of his major organs such as kidneys or liver. My father was suffering from a *culminative* health crisis.

The term *culminative* health crisis was foreign to me until 1978 when I attended a gerontology conference in Halifax, Nova Scotia. The lectures provided my first opportunity to understand the degree of physiological differences that exist between younger and older patients. The conference focused attention on the unique health care needs of seniors and the information presented changed dramatically the way I assessed an elderly person's needs for specific medical care and treatment. My new insight

awakened the critical need of considering *all* past health problems when assessing geriatric patients, as opposed to considering present health concerns.

From my experience as a nurse, I learned that the human body can tolerate a number of traumas or insults and bounce back or regain health. Following several of these crisis resiliency lessens and recovery becomes incomplete, leaving the person with some degree of lasting, residual damage or after effects. With the escalation of these traumas, the body is compromised to such a degree that recovery is no longer possible; organ failure occurs and the individual dies. The elderly have less resiliency when faced with a history of multiple illness events and they often die as a result of their culminative health problems instead of a singular illness.

From my knowledge of geriatrics and of my father's past health and illness history, I knew that this stroke was not his only problem. Dad had not felt well for years and he needed several medications to remain somewhat healthy. Dad's long term need for certain cardiac drugs contributed to his partial liver and kidney impairment. My elderly father was a perfect example of a patient with culminative health problems.

The network of blood vessels throughout Dad's body were narrowed by the effects of aging. He had partial cataracts in both eyes and his hearing was poor. He was tired and weak. On bad days when he was feeling discouraged about his deteriorating health, he would shake his head in defiance and remind anyone who was listening "that whoever said getting old was fun, was nothing but a g.d. liar!" Dad detested his own frailty and his inability to stop his body's aging. But now with his recent stroke, his body

was compromised too many times and his body was being *overwhelmed* by the culminative effect of many years of poor health. He could not survive this time.

Dad was aware of this fact and so was I. Our awareness of the impossibility of him living much longer was a constant emotional pain for me. I could accept the burden of knowing he was going to die, but I wanted to protect my father from the same knowledge. Knowing that Dad knew that his life was coming to an end and that his time spent with his family was also ending was painful for both of us. I loved my father so much that I never stopped wanting to protect him even when I knew there was nothing more I could do. My insight as Dad's daughter would be critical to his medical treatment and to the choices I needed to make with my family. As much as I needed to find a balance between what I knew as a nurse about Dad's condition and what I would tell my family, I needed to find a balance for myself. This balance was essential if I was to remain focused on what was best for him.

My father and I were like two sides of the same coin. I grew up hearing the words "*your just like your father.*" On one occasion when Dad and I were together, a friend of his joked and said that I looked like Dad wearing a dress. Dad was a loving parent to me and a cherished friend. We shared many common interests. With Dad's background in pharmacy and mine in nursing, we spent countless late nights sitting at the kitchen table sharing stories and discussing various health related issues prior to my move to Alberta. During these times, Dad often referred to his own failing health. His comments were candid and he spoke about his deepest fears. When Dad talked about his health concerns, what he said helped prepare me for this crisis.



During the last years of Dad's life, we often discussed the seriousness of his heart problems and his deteriorating health. Dad spoke of his fear of becoming disabled, either physically or mentally and he told me "I would rather be dead than to live like that." His eyes glistened with tears as he reminisced about old friends who had suffered strokes or had Alzheimers disease and now lived in nursing homes. He told me "That's no life. They're not living." More thoughtful about dying, he also spoke of his fear of dying in acute (severe but short term) congestive heart failure like his mother. More than thirty years after my grandmother's death, Dad's memories were vivid of her smothering and choking as her lungs filled with fluid and she struggled to breathe until she died. Dad mentioned the specific fears of these types of death frequently. His concern of dying with congestive heart failure or living with a stroke caused Dad more anxiety than the thought of death itself. Dad knew the feeling of this type of crisis all too well. By the time of this conversation he had infact experienced an acute episode of congestive failure. The attack was upsetting for Dad and the memory of that night left him with an enormous fear of it happening again. As a result of that experience, the fear of this type of death intensified his perspective.

This personal preference for one type of death over another was a common topic of conversation with elderly patients and their families. Even very old patients spoke about how they wanted to die. This concern appeared more important to them than their dying or even when their death might happen. This same concern arose in my conversations with health care professionals who witnessed death.

Based on their past experiences with dying patients or the recollections of the death stories from other friends, family or colleagues, physicians and nurses form their own hierarchy of ways they could die that were the most acceptable. Most common and most significant was the importance of a quick pain free death, as opposed to a prolonged and painful death.

Although I never mentioned this concern to Dad, I also thought about this notion of a hierarchy of dying — I thought about how I preferred him to die. As the other health care providers did, I also wanted a quick and pain death for Dad. During my nursing career, the majority of my elderly patients who had the same diagnosis as my dad died slow, drawn-out deaths. I witnessed these deaths and I did not want that for Dad. These real deaths bore little resemblance to the images in contemporary television programs and movies that are theatrical attempts to reconstruct dying which lead to families being confused by death and having unrealistic expectations of the entire death experience. Uninformed patients and their families are ill-prepared when faced with an actual death in their lives.

Today, discussions related to death and dying are becoming more commonplace but also more complicated. Never before has the family members' grief and concern for the well-being of a dying loved one been so complex because as Matzo (1997) suggests new technology gives the ability to either extend life or to terminate it. The living now have the capability to manipulate the event of dying in their search for a Utopian death where dying comes with dignity. As a result of medical innovations, people are more confused rather than more informed. Faced with the opportunity to discuss their own

mortality and the medical treatment they want provided before they die, many patients choose to relinquish these overwhelming, confusing decisions to their physician because they believe “the doctor knows best.” As modern dying (Nuland, 1995) continues to be a sanitized and packaged event, we as a society avoid the inevitability of death.

For my dad, his heart attack changed his life and he was transformed from being well to being sick. His illness shifted from acute to chronic and his self-awareness was altered. For over five years Dad’s heart damage forced him to live with the complications of an illness that affected his entire life. The stories he told us about his preferred ways to die were his attempt to reclaim some degree of control and individuality over an illness that made him feel more like a patient and less like a person. As an ill person Dad was taking responsibility for what this illness meant in his life through the telling of his stories (Frank, 1995).

Before his heart attack and being faced with his own mortality, the stories Dad told were about his past. Following his health crisis, the topics of his narratives changed and Dad began to weave different themes into his stories. Whenever our family spent time together, Dad would lament about his future. Through these words, he revealed his grief and end-of-life wishes regarding medical treatment. His stories, although no longer about his past, continued to teach us about who he was.

After 1991 when Dad had his heart attack, Dad and I discussed his choices about end-of-life medical treatment as part of his storytelling sessions. During his narratives, Dad would digress and ask about death and my experiences as a nurse working with dying patients. I told him stories of Palliative Care and explained the type of medical care and

treatment given to patients with life threatening illnesses and the support given to their grieving families.

As time passed and Dad's health deteriorated, I approached the subject of explaining his end-of-life wishes to his physician, so that the doctor would be well informed and better prepared when a crisis occurred. I also suggested that he consider speaking to his doctor about having a Personal Directive (Dossetor & Fraser, 1997) written that would reflect his final wishes and guide his medical care when he could no longer speak for himself. I stressed the critical importance of his speaking to the rest of our family so that they too could be aware of his wishes for medical treatment. I explained that our family would feel less frightened and less confused having this information when something did happen to his health. With the Personal Directive in place, we would be better able to help him receive the type of end-of-life care he wanted. The document would provide our family with confidence and certainty when making critical medical decisions because we would know the choices he would make for himself. We would be guided and empowered by his own words.

During these storytelling sessions, Dad's stories of the past identified his connection to that past, and the newer stories were more of his separation from the future and his preoccupation with his personal identity (Ross, 1998). His new stories were the result of his increased awareness of the limited amount of time he had left and the recognition of his own death. The new themes and stories were the closing chapters of Dad's biography intended to be useful but not to burden our family. They were to inform us and to make us content with our future without him. They were Dad's way of

maintaining a sense of autonomy and independence over his life, including its ending. Dad was making a purposeful decision to be the author of his complete narrative, including the final chapter. In doing so, he was preparing us to deal with the enormous anxieties and emotional demands of what would be his final health crisis. Although he made jokes about death and appeared fearless about dying, he always made it clear that he did not want to leave his family. He wanted to face death; if he had to die, he wanted to die on his own terms. He did not want to suffer. He valued a peaceful death over a poor quality of life. He wanted his final wishes to be remembered and supported by the family who loved him.

The slow fulfillment of his final chapter began when Dad had his stroke and he lost his ability to speak. His level of unconsciousness deepened and his ability to understand and interpret what was going on around him disappeared. The time had ended when Dad could interact with us. Those opportunities were gone. Dad's story telling came to an end.

Dad's dying experience was typical and unlike the frequent and romantic impression most people have of the dying patient being able to remain alert and communicative until the moment of death. As a result of this impression, there is a mind set that there will be time to talk and time to discuss the uncomfortable topic of dying and death before it is too late.

Listening to Dad was never easy for me, but as Frank (1995) suggests Dad's stories were giving voice to his personal dying experience. He was trying to guide the family that he was leaving behind. As a nurse I knew the stories could provide necessary medical information and as a daughter the stories made me feel closer to my dad. As teller

and listener of these personal stories, my father and I shared a unique opportunity to care for each other. His words provided me with the direction and clarity to make end-of-life decisions for him. In return he received the comfort of knowing his final wishes would be respected by those who loved him. When the time came that his life could not be extended, the guidance of his own words gave our family a sense of peace by fulfilling his end-of-life wishes and respecting his desire to die the way he wanted.

While researching this topic I asked many grieving family members if they ever discussed dying with their now deceased loved ones. I was never surprised when they answered “no.” According to Nuland (1995), this type of response is quite understandable. In his opinion, most people want to know the details about dying but few are willing to ask. Talking about death would give the impression death was accepted and it also opens the possibility of thinking it was welcome. Most people believe it is better to ignore such discussions (Mullens, 1997).

In my family, the practice of sitting together sharing time, laughter, and stories was something we took for granted. Regardless of whether the gathering together of family members was for a joyous occasion or for the mourning of the loss of a loved-one, we always had stories.

During our childhood and up until the time the stroke silenced his voice, Dad continued to share his stories with his family. Through his narratives, we learned the oral history and ancestors of the family, the connections to the past, and the recollections of our father’s childhood. On many other occasions, Dad’s stories served the more

intentional parental function of instruction. His stories taught his children about discipline and responsibility and the importance of learning how we should love and care for one another.

And it was through stories that Dad instructed us about his wishes at the end of his life. I was thankful that our family talked about death in such an informal way before Dad had his stroke. Before his final health crisis occurred our family was able to discuss Dad's death without feeling overwhelmed by fear and anxiety. We came to accept our father's death as a certainty but still hoped that it was something that would not happen for years.

In my years of geriatric nursing, I assisted many ailing patients and family members to manoeuvre their way through the often fast moving, confusing maze of medical protocol, rules, and regulations that further complicated their already upsetting situation. Many times the solution to their concerns was clarifying their own rights and responsibilities as a patient and a family member. My role as their advocate was to make certain that doctors heard their voices, that health professionals respected their treatment wishes, and that everyone involved followed their end-of-life decisions. When I helped to address their concerns, the majority of families achieved some sense of peaceful resolution with the reality that the death of their loved one was inevitable.

Now, I wanted to be with my family and assist them as they moved through that same maze of medical protocol and its accompanying emotional impact. It was now time to be an advocate for my dying father and the rest of my family.

As I travelled home I felt powerless and powerful at the same time. My love for Dad and my relationship to him as a daughter weakened my knees with absolute fear, while my knowledge as a nurse strengthened my sense of purpose. There was work to be done, decisions to be made and directions to be chosen.

In 1988 I moved 3,000 miles away from my family. Aside from our long and frequent telephone conversations and letters, our face-to-face, heart to heart family conversations were limited to my annual visits. My ability and my need to help support my family in their anticipation of the health crisis that lay ahead was limited. As a concerned daughter and an experienced nurse, I felt restricted in what I could do to help. The distance between my family and me became a nagging shadow that influenced everything I did.

In the past, it was not uncommon for me to take for granted the two intersecting roles of being a nurse and a daughter. Together the two roles were me, and I embodied them both. Whenever necessary I could switch my thinking from the perspective of daughter to that of nurse. I was not aware of the distinction between the two roles, but as Dad's condition became more unpredictable and his deteriorating health more visible, my insight as a nurse and my desire to care for my own grieving family increased. I became aware that I listened, watched and waited *like a nurse* for any opportunity to help support my family through this crisis. My father became my patient and my own family became the grieving loved ones.



My education as a nurse stressed the need to remain professional and distant from my patients. The professional ability to stand outside a situation while continuing to function within it encouraged objectivity that ensured equitable treatment for each patient.

My dual daughter/nurse perspective strained my ability to maintain this distance and I was aware of the conflicting expectations between the two roles but also the conflicts that existed within the expectations of the nurse and the daughter. Travelling home I was willing to use my knowledge and skills as a nurse to support his need to die with dignity. But, as his daughter I wanted him to live forever.

## Chapter Four- Courage to Change the Things I Can

### Journal Entry - December 17, 1996: A Shared Journey

I came to your side with the knowledge that I could not stop death, but I also knew that I had the skills and the capabilities to challenge your end and take the sting from your leaving. I entered your death journey along side of you. I wanted to help you die with the peace and dignity you had wished for.

As I waited for my already late plane connection to arrive, I was overwhelmed with what I might need to say or do for my family when I first saw them. My blood screamed through my veins. My head throbbed and my heart raced. A voice in my head taunted me — *You're a nurse! You have seen all of this before.* I attempted to rationalize Dad's stroke into something less than it was, but the cruel reality could not be denied. I anticipated this day for many years and it finally arrived.

The beginning of my father's dying process began on July 3<sup>rd</sup>, 1991, when he suffered a severe heart attack. Dad survived this heart attack, but the hope of a full recovery to good health was not possible. Dad's damaged heart muscle could not be repaired. Even after open-heart surgery, his heart remained damaged and weakened. Everything that could be done medically, was done. For the next five years of Dad's life, my mother, brothers, sisters, and I attempted to brace ourselves for what lay ahead for him and for us, as his heart condition worsened and his health became more unstable. The heart attack changed Dad's life and the lives of the family members who loved him.

Since the heart attack, whenever Dad's health appeared to improve, his sense of hope and ours too was renewed. However, when his health faltered and the seriousness of his heart condition resurfaced, our hope was shattered. Feelings of fear came and went. Trust in having a future with Dad slipped through our fingers and disappeared. Hope became both an encouraging, comforting friend that tantalized our emotions as well as an untrustworthy, noxious adversary that left us angry and confused. Dad's heart disease influenced our families' lives almost as much as it did his. My mother, brothers, and sisters, and I shared our worries when Dad experienced further health problems, and together we celebrated each day and each week that he stayed well.

For more than a decade, our family lived the emotional roller coaster that affects the lives of an ever increasing number of adult children of aging parents. Each time our father's failing health moved into another crisis phase, our lives mirrored the depth of that emergency. Fear and anxiety held us captive and we returned to our parent's home, frightened and anxious and prepared for the worst.

In the earlier years, after the heart attack, when Dad's health was frail but still satisfactory, our family's perception of the worst was death. Later on as time and illness ravaged mentally and physically at his body, our perception of what constituted the worst changed. Dad's conversations that once emphasized his desire to be kept alive no matter what the consequences also changed. As his quality of life became more compromised by his chronic heart disease, he shared with his family his desire to die without medical intervention. He said he was tired, and that for him to exist in a life that had little quality and even less hope for improved health was the worst that could happen to him.

Following Dad's heart attack, the downward trajectory of his deteriorating health and our families' anticipation of his death were inseparable. All aspects of our family life became complicated by a mixture of fluctuating intense interactions and emotions associated with our anticipation of loss. The persistent fear of Dad's death eroded any sense of equilibrium within our family, and the dreaded awareness that we could do nothing to prevent Dad's eventual death was uncompromising.

Dad's chronic ill health demanded constant time and attention. The topic of heart disease became an incessant concern in our homes, in our thoughts, and in our conversations. Fear, concern, and a sense of vulnerability filtered throughout our family's once safe environment and we were hyper vigilant regarding Dad's chronic poor health. Our shared sense of apprehension altered our identity as a family. We lost our ability to feel secure in our day-to-day lives. We all lived with the thought that at any moment, night or day, no matter where we were or what we were doing, our lives could be interrupted by the same illness that controlled Dad. We struggled to prepare for the uncertainty of never knowing when another crisis would happen.

During my nursing years in long term and palliative care, on numerous opportunities I worked with individuals and families regarding their loved one's deteriorating health and impending death. Often, these family members experienced years waiting for death to occur. Time after time, these families tried to physically and emotionally prepare themselves to face a death that did not happen.

Year after year, many families relived this waiting scenario. Time after time, they hurried to their dying relative's bedside, anticipating death. Then, for whatever reason,

their loved one survived the crisis, and the grieving family returned to their heightened state of anxiety. Frustrated, an unsettled sense of readiness and anticipation for the next crisis to emerge, marked their lives.

For my family, this period of *anticipatory* grief (Rolland, 1994) began when Dad had his heart attack and continued for us until his death. For five years this stage of grief controlled my life, the lives of my brothers and sisters, as well as my mother's and father's. Together we shared this unique form of grief that few people understand and that even fewer appreciate its impact upon a person's life (Rolland, 1994). The anticipation of a loss can be as painful and as challenging for families as the actual death of their loved one because such families face the enormous challenge of trying to live with the persistent uncertainty caused by an impending tragedy that threatens their lives.

From an outsider's perspective or from those not affected by the emotional ups and downs of anticipating the occurrence of a devastating illness, disability, or death, anticipatory grief is difficult to understand. To many observers, this condition is the result of emotional instability, an over-active imagination or irrational thinking. The complex emotional fluctuations between positive states of hopefulness and painful feelings of desperation and disappointment are powerful waves that influence the lives of everyone involved in the ailing patient's life. Family members and close friends exist in a perpetual emotional turmoil that they cannot control or sometimes even recognize.

Anticipatory grief appears to be more difficult for outsiders to understand because of the label "grief." Many people associate "grief" with the feelings that occur following a death. Therefore, when there is no death and there is an absence of a body people then

perceive incorrectly the anticipatory grief to be an unjustified response to an unreal loss, and expect a defense from the family members for their grief feelings or behaviors. This leads to further complexities when grieving people begin to conceal their anticipatory grief in an attempt to avoid appearing over-sensitive, weak, or irrational. Such concealment magnifies the situation and the individual anticipating a loss feels further misunderstanding and more isolation. The anticipatory grief I experienced for my father was devalued by several people who suggested "I enjoyed making-up things to worry about."

I also realized that the *age* of the ailing person influences an outsider's perception with respect to anticipatory grief. Whenever I mentioned my father was almost eighty years old, my anticipatory grief comments often produced an awkward smile by the listeners, accompanied with their words of "What do you expect?" My grieving about anyone over seventy was perceived as a waste of my emotions and time. I soon sensed that these people did not consider the love and the wonderful relationship that existed between my father and me, regardless of his age. I realized that this was my grief and that very few people wanted to hear about a daughter's sense of helplessness and loss at the thought of losing an elderly parent.

The entangled feelings associated with anticipatory grief albeit overwhelming and unpleasant, became a way of living for me. For five years I existed in a type of personal hell. I was torn between the constant paradox of not wanting to receive that dreaded late night call informing me that something had happened to Dad and the desire to have this terrible, nagging anxiety stop. These thoughts made me feel guilty thus making my grief an endless cycle of emotional unrest.

When I first arrived at the hospital on December 17, 1996, I was torn between walking to the second floor to delay arriving at Dad's room or running to his side as fast as I could. My fear was as much a result of what I anticipated I would see, as it was of the dreaded next step in Dad's medical care. Coupled together was my most frequent whispered prayer of wanting to be by Dad and my worst nightmare of Dad dying.

Within my first hour of arriving at my Dad's bedside and looking into the frightened, exhausted faces of my family sitting in their quiet vigil, we were faced with the most critical and difficult decision that we ever had to make. We sat as Dad's children in a ugly furnished, tiny waiting room and discussed what we wanted the physician and the nurses to do if and when Dad's heart stopped, when it went into cardiac arrest again. I remember the looks of dismay and defeat which intermingled with the tears and trembling lips of my family as we talked and whispered together. These were my brothers and sisters; their pain was my pain.

Speaking as a nurse, I needed them to understand the physical and ethical implications of resuscitating our father when he went into cardiac failure again. I needed their answers now; we had no time to consider and reconsider this issue. The privilege of time was stolen by the seriousness of Dad's heart condition. The fear and anxiety in my voice as I spoke emphasized the urgency of this decision. *"I cannot let you go home tonight without making this decision. We have to do this for Dad."* The deafening silence filled the empty spaces in the little room, and I waited for their reply. We all knew that regardless of their answer, we would lose him.

Jane's words still resonate in my ears and heart "*This means we are giving up: this means we are going to let him die!*" she bowed her head and stopped talking. Her sobs smothered her breathing and leaving her unable to speak.

I struggled to answer her to the best of my ability "*No hon, this will be our way of loving Dad to the very end.*" I needed my family to know what resuscitation was like. I needed to share some of the sad stories that nurses tell about attempting to resuscitate frail and elderly patients. I needed the stories to help make this real for my family and to help them to understand what it would be like for Dad if we did not make this decision.

I explained nurses' stories of the dilemma they experienced when either the families or the patients would not, or for some reason, could not, bring themselves to tell their physician that they did not wish to have their loved ones resuscitated, that is a do not resuscitate (DNR) order. The stories described patients with fractured ribs and the frail bodies burned by the electric paddles, in addition to their own trauma from witnessing an induced convulsion. Nurses have described these experiences as nauseating and as dehumanizing for the nurse as it is for the patient.

Without exception these very caring nurses in-private questioned their own actions in carrying out the resuscitation order in the first place. Some tell of the unsettling images of those experiences and how those memories continue to haunt them to this day. Movies and popular culture romanticize many of the medical procedures associated with dying, but nurses share none of these distorted perceptions.



Looking across the room into the familiar faces of my family I tried to find some way to use what I knew as both a nurse and a daughter to guide us through this crisis. I needed my knowledge as a nurse with personal experience helping resuscitate elderly patients to support my family in their decision, but this was difficult for all of us. We sat together in silence and struggled to make sense of this heart-breaking experience. In a perfect world, no child would choose to be in this position but Dad's physician had encouraged our family to assist the medical team by providing Dad with comfort and dignity. In making this decision, we were trying to provide him that comfort and dignity.

From my nursing experience, I was conscious that whatever decision my mother, brothers, and sisters made regarding Dad's treatment, it needed to be made without pressure from me. As a nurse I could provide them with the information they needed to help with making a decision, but it was important that their own awareness of Dad and his emotional physical and spiritual needs be part of the choice they each made. Their knowledge of Dad's beliefs, values, and ideas of what was important to him was their reference in making this decision. I knew what I thought my family should decide but I could not force them to make a choice that they might later regret. It was important to me as a nurse that each family member be aware of what they were choosing and that each feel free to decide without concern about the wishes of other family members.

Decision making and problem solving of this magnitude within a family is challenging. End-of-life medical decisions can stress a family's ability to cope as a unified subsystem and may result in conflicts or relationship breakdowns among family members that may never be resolved. In my years in geriatric nursing, I witnessed many conflicts

where members of the same family refused to speak or even visit their dying loved one at the same time as another relative. In more extreme situations some family members made medical decisions independent of other relatives, and in secret, presented themselves to physicians and nurses as the “power brokers” (Simpson, 1996, p. 86) for the entire family. I am determined this would not happen with our family.

As a daughter, I shared my knowledge about Dad with the family. As a nurse I tried to find a gentle way to share my professional experiences from similar past situations as to my dad’s. Webster and Murphy (1999) describes this blending of knowledge as the reciprocal nature of relationships necessary between health care professionals and family members and that decision making must be based on what is best for the patient and not about who is more “powerful” or “smarter” (p. 1).

According to Wedel (1999) *wisdom* is a different kind of knowledge that must be utilized when making medical decisions and it is an introspective element that comes from within. Wedel describes this harmonizing of knowledge and wisdom between health care provider and family member or patient in a partnership as “magical and more significant” than most of us to know or understand.

My own awkward journey into understanding the issues associated with making medical decisions regarding life and death began authentically early on in my nursing education. But, considering a patient’s death over their living was not something I accepted.

When I was a novice nurse, I felt a deep sense of personal and professional failure whenever one of my patients showed an inability to thrive and died (Newbern, 1992).

Regardless of their advanced age and complicated chronic health concerns, I questioned my own capability of ever being what I considered a good nurse. I re-examined my motivation to remain in geriatric nursing. I struggled with my own sense of inadequacy and my desire to provide a high standard of ethical and compassionate elder care. My feelings were not unique.

Historically, health professionals believed that their true measure of professional success depended on their ability to cure their patients. Any physician unable to cure or save a patient's life was considered a failure or at least less capable than other more successful doctors. This "cure at any cost" mind set failed to consider the value of other factors contributing to quality patient care, such as pain management, symptom control, emotional care, and spiritual support. And, this mind-set was heightened in cases where death was unavoidable.

For decades, nurses and physicians were torn between the prevailing philosophy of maintaining life at any cost and their personal sense of what they perceived to be ethical and moral practice. Slowly, a desire to provide dying patients with dignity, comfort, and compassionate care increased, and health professionals began to examine the complex issues that arise when cure is no longer possible. I explained to my brothers and sisters — while they were struggling to make their decisions, how many nurses have vivid memories of special moments when a learning experience occurs that produces significant long lasting effects. I, too, benefitted from a nursing experience that taught me about comfort and compassionate care.

Although the event happened almost twenty-six years ago, the memory of that special day remains clear. The patient was a frail eighty-two year old lady with lung cancer. The cancer had spread throughout her body and there was no hope of a cure. She was dying. As I entered her room I noticed that she had stopped breathing. I panicked. I checked for her heart beat and there was none. I was frightened and alone in the room. I was a young nurse with little experience with such situations, but I felt compelled to do something. I felt obligated to help in whatever way I could. I did not stop to think as I flattened the bed, removed the pillow from under her head and prepared to compress her pale boney chest. Just as I was about to clasp my hands together in the Cardiac Pulmonary Resuscitation (CPR) position like I had been trained, I stopped. I moved my hands away and thought about what had happened. I reprimanded myself in a whispered voice and questioned "what was I trying to do." She had died so peacefully. For the next few moments, I stood beside her bed and thought about what I had come close to doing.

This incident was fixed in my memory as a significant milestone in my professional growth and my sensibility toward the real life issues of a person's quality of life and their peaceful dying. On that day I became aware of the critical importance of always striving to ask the question "*What is best for the patient?*"

Patients and families still continue to demand that their physicians keep them alive regardless of how the lifesaving medical procedures might effect their resulting overall quality of life. The perception that modern-day technology can restore or at least repair any biological problem is not uncommon. Nuland (1995) suggests that society can now deny the power of not of death but of nature itself. This attempt at immortality suggests that

many people appear to foster a greater personal fear of dying than they do living a negative quality of life void of either physical independence or mental clarity, and therefore continue to choose to avoid death at any cost. Our father was not one of those people and as his family we knew the choice he would make and we knew what we had to do.

There were no words to describe what we were feeling. The emotional pain of losing Dad combined with our deep love for him and loyalty to follow his final wishes overwhelmed our thoughts, leaving no room for anything else. One fact remained constant, with or without our decision our father *was* dying. The reality of knowing there was no choice other than support his comfortable death was bitter-sweet. Our thoughts and feelings were private and chaotic.

Jane's voice raged in desperation toward the emptiness of the center of the room as if to challenge face-to-face the invisible but real presence of death, "*I feel like taking that goddamn chair and throwing it through that goddamn window!*" Jane's words echoed the fury and raw anger she felt from not being able to fix Dad and take him back home like she had done so many times before.

Jane's feelings of self-reproach and guilt over not being able to prevent Dad from dying was a common experience that I observed in family members of many dying patients. Grieving sons, daughters, and wives often assume some degree of responsibility for having the influence or power to prevent the death of their loved one. When they fail to do so their sense of duty or obligation becomes burdensome and the resulting feelings of guilt are long lasting.

Jane's sense of duty toward Dad and her desire to protect him from further health complications were not new. Jane's active involvement in Dad's medical care intensified as he became unwell. In my absence, Jane became the eldest daughter living at home or at least in the same town. Taking on the role of overseeing Dad's care appeared to be a natural progression for Jane and she soon joined the rapid increasing number of adult-children providing some level of informal care to their elderly parents.

Six months before Dad had this stroke, Jane spoke to me about her feelings of helplessness because of her inability to stop the escalating pace of our father's deteriorating health and certain death. The passage of time and Dad's increased frailty had altered Jane's relationship with him and their parent/child roles were transformed. As Dad became more dependent on Jane, her own sense of her responsibility toward protecting his well being increased. She became his protector, his advocate, and his confidant. Illness had changed the way Jane related to Dad and she often described him as being vulnerable "like a little boy."

As for Dad, his reliance and trust in Jane's ability to care for him during the last five years of his life created a positive bond between them. This closeness distinguished Jane's relationship with Dad from my mother, brothers, sister, and me and further intensified her sense of guilt when faced with his dying. Thinking she had failed to fulfill her responsibilities to Dad, Jane was as angry at herself as she was with the fact that he was dying. Agonizing about her feelings, she cried "*Jesus I hate this! I hate not being able to*

*make him well again! I hate watching him get so little; it's like he's disappearing right in front of my eyes. I just love him so much. I don't want anything to hurt him."*

Jane's words reflected the change that Dad's chronic illness brought to their adult-child/ elderly parent relationship. Although still very much a grieving daughter Jane spoke as Dad's guardian as a loving parent would of a cherished, unprotected child.

This "shift in role function" (Rolland, 1994, p. 224) between Jane and Dad evolved from their mutual affection and respect for each other and between them they had created a "reciprocal relationship of care." Dad needed Jane's watchfulness and support throughout his illness as much as she needed to be there for him. My mother, my brothers and my younger sister were grateful for Jane's desire and ability to participate as our father's advocate. Each of us was aware of Jane's deep desire to be involved with Dad's medical care and because of this we also understood her anger. None of us were shocked at her outburst.

As a daughter, I envied Jane's blunt honesty. I envied her ability to verbalize her anger while I sat in my own fog like silence with our brother and sister making no attempt to respond to what she was saying. In her own display of grief, Jane was saying what I was already thinking. My words seemed inadequate as we sat together in silent thoughtfulness and remembered our dying father and the life he lived.

In my experiences in geriatrics and palliative care, I worked with numerous family "lay caregivers" (Ruppert, 1996, p. 40), the majority of whom were female. In speaking with these women it was clear that the responsibilities for caring for their ailing loved-one

became the inevitable responsibility of the female members within their families. When there were no daughters in these immediate family units, the role of caregiver was often assumed by a son's wife. In some situations this responsibility was not a matter of choice for the daughter, daughter-in-law, or wife, but an expectation of the woman's role within the family, a responsibility that could not be avoided without ramifications such as alienation or divorce. Older women, were perceived to be a "natural resource" (Robinson, 1997, p. 7) within the family regardless of other responsibilities such as the care and nurturing of children and grandchildren.

The term "lay caregiver" (Ruppert, 1996, p. 40) refers to the estimated 200,000 parents, spouses, and siblings in Canada who either assist with or oversee the care of an elderly family member. These familial caregivers face challenges caused by the increased demands of caring for aging parents who are living longer than in the past and experiencing more complex and chronic health problems. Often these family members are expected to acquire overnight the necessary knowledge and skills of a para-professional health care provider. These skills are necessary to provide the level of care required by a loved one who otherwise would have been transferred to a hospital or chronic care facility.

As a nurse in long term and palliative care, I was surprised by the high degree of knowledge and skill I observed in several family caregivers. In many incidences, these lay caregivers performed patient care tasks with an apparent degree of knowledge, capability, and appropriateness comparable to health care professionals. Whenever I commented on how well they carried out a specific care task, such as repositioning a comatose patient, the



answer was often a simple “*Well you just do what you have to do and after awhile you get it right.*”

These family members appear to have such a sense of love and regard for their loved-ones that any thought of *not caring* for their needs was unacceptable. Providing care to someone they loved was an expression of their love for that individual. It was a function of their personality and it was their way of coping. One grieving wife shared with me that she did little things for her dying husband like massaging his feet, in order to help ease her own sense of helplessness because she could do nothing else.

As a nurse I appreciate how difficult it was for many family members to be caregivers. But as a nurse and a daughter, I also knew how difficult it was for me *not* to be able to be my own father’s caregiver. The 3000 miles that separated us made my ability to provide physical care for Dad during the last five years of his life unrealistic. My sister Jane was my hope for knowing that our father would receive the medical care and attention he required. I knew that Jane had the forthright personality, the know-how about the medical bureaucracy and the persistence needed to oversee Dad’s medical care. I knew if anyone in our family was capable of advocating Dad’s medical needs, it was Jane.

When I moved to Alberta in 1988, Jane and I spoke about Dad and his failing health. I was afraid to leave and I felt helpless. I wanted to stay close to Dad and watch over him but that was not possible. Before I left, Jane promised me that she would never hide anything from me regarding Dad’s health and that no matter what happened. Even if it appeared unimportant or insignificant that she would always tell me. Finally, she promised never to protect me by shielding me from the truth, but to always tell me everything she

knew about Dad's condition, as well as everything she was thinking and feeling about what was happening to him, if and when his health changed. I left, placing my complete trust in Jane to always care for our father the best she could.

Having Jane be my eyes and ears to watch over Dad while I living in Alberta was often the only reassurance I had. Whenever Dad experienced a medical crisis I knew my mother, my brothers, and sisters were with him, but most important to me I had faith in that Jane would *fight* for whatever he needed. I knew my sister; I knew she was as capable a caregiver as I had ever seen.

As a nurse it was my experience that the words *caregiver* and *advocate* are often mentioned without much consideration of the enormous responsibility that the two roles entail. "Care-giving is already one of the biggest issues of the next century for families" (Underwood & DeMont, 1991, p. 31). The responsibilities of being a caregiver whether it includes actual hands-on care or an advocacy role can be overwhelming. Lay-caregivers often experience feelings of frustration and anger. Many feel abandoned by other family members and friends and ignored by the health care system on which they depend. They live in a persistent state of worrying about their loved-one and struggle in anticipation of what could lie ahead. Often, family members referred to these two roles of caregiver and advocate "as the most difficult things they had ever had to do."

Looking across the room into the tear-filled eyes of my sister Jane, I realized how much I contributed to the stress she was feeling and to the anger she verbalized. As our father's advocate and overseer of his medical care and treatment she fought frequent, tiresome battles with Dad's doctors and nurses without my help. For almost eight years,

Jane did everything she could to care for Dad and to make certain his medical needs were met and now she was exhausted. I was grateful I was home to care for her also.

In the little waiting room, Jane began the conversation we needed to have. A voice broke the uneasy silence and one by one we each offered our tearful support in our shared decision not to pursue life-sustaining procedures such as CPR. Instead, we choose comfort and peace for Dad until the end. Mom was not with us because she was home attending to the younger grandchildren, so I spoke to both her and my brother over the phone about their need to be part of the decision. Mom cried as she agreed "*Yes, we agree, your dad would not have wanted to live like this. He would not have wanted CPR.*"

Dad's physician thanked all of us for making this difficult decision which was legally recorded on Dad's chart. The doctor informed us that without this type of guidance he would be unable to provide Dad with an appropriate type of medical care. Dad would now receive the type of care required to address his failing health needs and yet permit his death to occur without *medical intervention*.

Our dad was now a Palliative Care patient and rather than receiving active treatment where the goal is to achieve a cure or an improvement, he would receive care and procedures associated with a palliative philosophy. This meant that my family was no longer fighting to prolong Dad's life, but we were instead providing him with peace and comfort until his life ended, whenever that end would come. Where our sense of hope was once focused on Dad's survival, it now shifted to him living with comfort and dignity for as long as he could, coupled with the hope of him dying in peace.

Our decision, though difficult, provided our family with the expectation that Dad would experience the peaceful death of which he had often spoken. As Dad's family, we considered our choice a final gift of love to our father who had always cared for our needs.

Although this major decision eased some emotional strain, we were still a family struggling to face the day-to-day changes in Dad's deteriorating condition. Our anticipatory grief and uncertainties about the looming loss took control of our lives and moved us forward like robots. We all needed to continue our lives without the burden of feeling that we did not place Dad's needs for a peaceful death before our needs to hold on to him. We needed to survive this relinquishing of hope and be able to reflect on the decisions and the events of this difficult day in a balanced manner.

We could hope that these hours and days of emotional pain and helpless anxiety would not overwhelm our cherished memories with Dad in healthier and happier times. We needed the reassurance that Dad was not in any discomfort and we needed to know that we had done our best for him. We needed to integrate our experience of the dying process into our lives with our feared anticipation of tomorrow. Later that same evening as we visited, it was evident that although we had each based our decision on our love for Dad it did not make the choice any easier.

The decision to not resuscitate our dad was our immediate family's first real loss of hope and we struggled to find any comfort in Dad's impending death. As a family we were trying to care for Dad and for each other the best way we knew how, and according to Nearing (1995) we were not alone.

Just as the last stages of one's life can be a shiningness or shadowed, so the act of dying can be bright or dark. It can be a harrowing ordeal or a hallowed happening. As we can live into our old age with consideration and grace, we can approach death with minimal distress, meeting it with dignity and deference. There are techniques for dying well, just as there are for living well. There are ways of transition, sane approaches to death.

We can make a conscious and worthy exit. Dying can be a natural and desirable process, a happy act, a rendering back to the whole what has been separated for a time — a willing and glad restitution, almost a celebration of successful aging. (p. ix)

## Chapter Five - And The Wisdom to Know the Difference

### Journal Entry - December 17, 1996: A Nurse's Knowledge

I cared and instructed so naturally, so instinctively that *the daughter* barely had any opportunity to even think - yet come close to feeling . . . . Maybe this was the only way possible that I could have survived (as the daughter).

It was *the nurse* who carried *the daughter* through this hellish experience. It was the knowledge and the strength of the nurse alone that transported the daughter away from this painful reality.

In that hospital waiting room, our family supported Dad and his final wishes. Sitting together in tearful silence with my sisters Jane and Lisa and my brother Donald and we all struggled to find the courage in our hearts to understand the decision we just made. None of us spoke as we got up from our chairs and left one at a time and walked down the corridor back to Dad's room. So much had happened in such a short time; seeing Dad's face again broke my heart. He looked so defenseless, so shattered, lying pale-skinned, silent and still. I knew that I would never see his eyes flash with excitement as they did when he welcomed me home in the years prior to his stroke. I would never hear his voice call me by the nickname that no one else uses or feel his arms around me.

Using the observational skills I sharpened over years of walking into similar situations, my eyes took in the entire room with one sweeping glance. The scene was all too familiar and as a nurse my understanding was immediate. In long term care I saw many

patients die, and Dad now had that same look of approaching death. His body already appeared lifeless and the beginning signs of his impending end were present.

In the six months since I last saw Dad, he lost a great deal of weight. Under the profile of the crisp, white hospital sheet the thin outline of his boney shape was noticeable. He was lying on his back with his arms and legs awkward and straight as if restrained. His face was pale and expressionless except for the telltale trademark of the stroke causing the right side of his mouth to droop. His eyes were closed. The sound of his breathing was almost inaudible and the silence he embodied filled the room.

His physical condition was no shock me because I understood the irreversible series of normal biological events that precede “somatic death or death of the body as a whole” (Durham & Weiss, 1997, p. 44). I also knew that the cause of death depends on the existence of a specific disease process that is different for everyone and that there are physiological changes that occur as a person nears death.

During my experiences in Palliative Care, I often observed nurses escorting first time visitors into a patient’s room. The nurses’ purpose in accompanying these new visitors was to prepare them for the unfamiliar, sometimes disturbing appearance of the dying patient and to provide information about any medical equipment being used. As a daughter I was unprepared and vulnerable when I walked into my father’s room, but as a nurse I anticipated such an appearance. I was the frightened family member and the calm, medical professional.

Walking into Dad’s room and seeing his face, the shock of his appearance confirmed my worst fear that he was dying. Seeing my tear filled expression my brother

tried to console me as I covered my mouth with my hands to smother my outcry. Donald's voice was soft and kind but I did not listen. What I saw frightened me. I felt helpless and out of control. I was falling apart in front of my family who I wanted to help yet it was me who needed reassurance. This was so unlike the nurse in me.

One of the fundamental skills I had learned in my nursing education was the ability to appear composed and in control when faced with even the most unsettling situations. I was taught to conceal feelings of fear, anger, anxiety, and shock behind an emotional neutral facial expression. Regardless of how overwhelmed I was by the situation, no one was to know how I was feeling, especially not my patients or their families.

As a nurse it was my responsibility to set an example of calm for those in crisis. Families and patients took their cues from my expression, behavior, and attitude. If I as their nurse showed fear when a crisis occurred, their anxiety would be intensified and their confidence shattered. Throughout my training this ability to perform as a consummate professional was emphasized as essential to my nursing role and responsibilities. I understood and accepted this standard of practice but at times had problems maintaining that professional facade.

During the final year of my nursing education, a supervisor noticed tears in my eyes moments after I gave a dying woman an injection for pain. I was lectured about my unprofessional behavior and was informed I had to "toughen-up," that I was "too soft to be a nurse." She predicted that I would be unable to support patients or families who needed to rely on me. After all those years, I was remembering those words of warning, but I was still unable to focus on what was happening in my dad's hospital room from the sole



perspective of an objective nurse. This patient was *my father* and I was responding as a daughter not as a nurse. I was grieving the loss of the relationship I cherished between us.

Dad's presence always made me feel secure. And now, I needed to surround myself with that comforting familiar closeness but the hospital bed-rail encircled Dad inside a boundary that stated he was no longer part of our family. This separation marked the citizenship that exists between the two kingdoms of those who are well and those who are sick (Frank, 1995). Dad's illness made him a citizen of the ill and he became the *property* of the hospital. The bed-rail maintained a distance between us protecting the orderliness of the regimented, institutional environment. I knew that death would soon take Dad from me and I refused to accept the bed rail boundary and its latent message.

To challenge the institutional environment, I collapsed the bed-rail that separated Dad from me and I climbed up beside him, cupped his semi-conscious face in my hands, and tried to waken him. "*Dad, it's Sanie! I love you Dad! I came home! We're all here. All your kids are here!*" For a split second Dad half opened his eyes, and smiled with the left side of his face. Satisfied that he heard and understood what I said, I laid down next to him resting my head against his shoulder. I felt Dad's frailty against my skin. I also knew the message my nurse's senses were now giving me; I needed to feel the beat of Dad's heart. Placing my finger tips on his wrist I listened. I came to Dad's bedside first as his daughter, and now as his nurse.

Dad's pulse raced and slowed in an irregular pattern against my listening fingers; his heart was weak and struggling to keep beating. Trying not to disturb him or to upset my family anymore than they were, I slid my hand up Dad's arm, across the right side of his

chest, and rested my flattened palm over his heart and closed my eyes to deepen my concentration while listening to what I felt.

Dad's heart rebelled against my intrusion. The force of the struggling beat moved beneath his patient gown, against my hand. Everything I learned about Dad's heart condition rushed through my consciousness. And I knew the simple facts. *No one could survive with a heart rate like this. Dad's heart was fighting a battle inside his chest that it would never win. Eventually, it would exhaust itself and stop. His heart was wearing down as I listened.*

I now had a better idea of what was happening with Dad and even a glimpse of how he might die. I knew I could no longer fight to save Dad's life. Although losing him to death would be heart breaking, I knew that giving him up to the experience of a painful death would be intolerable. It was very clear, my singular purpose was to help my father die with peace and dignity. I was prepared to stay with him until that happened and to help my mother, brothers, and sisters through this difficult time. This all seemed so unreal to me, I could not image what the rest of my family were feeling.

#### Personal Reflections - December 17, 1996: A Family's Decision

Despite my unfamiliar feelings, the hospital is familiar territory. As a nurse the words Do Not Resuscitate are common to me. The bureaucratic rules and rituals of the health care system are part of my professional education. Although we were experiencing Dad's dying as a family, my understanding of the situation is very different from my mother, brothers, and sisters. My experience as a nurse with other dying patients influenced my expectations. This was the first death experience for my family and the significance of this event for them

was increased because it involved the loss of a loved family member. The combined effect of these factors could place my mother, my brothers and my sisters at increased risk for experiencing unnecessary problems grieving when death does occur and their expectations of it are not met.

The first hours following any health crisis are the most difficult. This is when families are faced with the burdensome task of trying to decide what type of medical attention and treatment they want their loved one to receive. Unfortunately, families are required to make these important *life altering* decisions at a time when they are surrounded by a medical environment which is foreign to them.

During these stressful times, family members are frightened and shocked by the seriousness of the health crisis. In combination with these emotions, relatives are often overwhelmed and unprepared to deal with the sheer responsibility of making medical decisions of such enormous importance concerning their loved one's life and death. Instantly, crippling emotions envelope family members and the powerful, unfamiliar health care environment adds to their staggering emotions.

Health professionals are often unaware of what families in crisis are experiencing. The same environment that overwhelms patients and their families is a comfortable one for nurses and doctors because it is their work place. The hospital reflects their professional status and promotes their distinctive roles, responsibilities, and positions in the hierarchy of health care providers. As a result of this familiarity, nurses and doctors perform their health care duties and obligations for their patients and their families in crisis, without giving much

consideration to their own professional authority and power which they may take for granted.

The medical culture isolated families from patients in a purposeful way thus allowing health professionals to promote, protect, and maintain their roles, responsibilities, and power. In health care the adage “information is power” (Simpson, 1996, p. 86) reveals the complex and political nature of medical care. This is the foundation of the internal paternalistic philosophy which divides a health provider from a health consumer. Imbalance between those who have medical information and those who do not persists today in the provision of universal health care. The authoritative practices of many physicians and nurses toward patients affects all groups regardless of their socio-economic background.

Although some areas of the health care system appear to give lip service to the philosophy of encouraging and supporting client/patient and or family education, many health care professionals are reluctant to change. Members of the profession continue to believe that their professional ability to provide care to patients is less complex, if and when, there is no debate concerning who makes the decisions. This perpetuates those in power remaining as the “gatekeepers” (Weiss, 1992, p. 66). They are the controllers of all medical authority and decision making. In this situation, knowledge remains in the hands of a limited few and jeopardizes the involvement of family members in decision making. Without improved patient and family education, health care consumers will have little autonomy in making medical decisions, despite the fact that the freedom to make well-informed choices is essential when a patient is dying.

As a nurse in long-term care, I am well aware of the perceived powerlessness of dying patients and their families. I witnessed *blatant* disregard by the active treatment hospital environment for the grief needs of dying elderly patients and their loved ones. Some health professionals refer to many seniors in derogatory terms as “bed blockers or Gomers” (Fox, 1989, p. 128) and consider the treatment of their illnesses as impractical and uneconomical. Their complex intractable illnesses and irreversible mental deterioration prevent such patients from returning to their normal adult roles and physicians often want them discharged. This prejudiced attitude can extend to include some nursing students who have stated unapologetically that they spend less time with dying, elderly patients because of being too busy. These nursing students consider their time spent with other patients to be more productive and rewarding.

During the final years of Dad’s life when his need to be hospitalized occurred more often, inevitable discussions with medical staff revealed a belief that viewed his age as problematic. This attitude of *ageism* by physicians and nurses influenced the type of care he received. Many health care providers appeared to see my father as an old man; they assumed he had lived a full life and was ready to die and therefore limited the treatment options presented to him and our family. As a result, it was necessary for us to spend hours arguing with Dad’s physician about treatment options which distracted us from spending our time with him and intensified a difficult situation.

Age is an important factor in health care decisions and to suggest otherwise is naive. As suggested by McCarron (1991) age is a biographical medical standard to be compared to

the predicted outcome of a treatment. When the ethics of age are considered as a criterion, medical treatment should not be used to resist death but be limited to the relief of suffering.

For my elderly father, the significance placed on his age was an important consideration in the decision making process regarding his end-of-life treatment but it was *not* the singular factor for choosing the Do Not Resuscitate order. Speaking with concerned family members of unwell elderly patients I emphasized the new health care environment where patients receive what they or their family negotiates, rather than what a physician alone decides. Being aware of what choices they are making, feeling free to do so, and choosing intentionally to do it are important in any health related decision. When recovery or cure is no longer possible, families must be able to interpret all relevant information in order to make treatment choices that are appropriate to the present crisis, as well as to support their grieving when death occurs.

Since my father's death several people shared with me their recollections of the death of their loved one. Years after the loss, they continue to experience guilt and regret associated with the end-of-life treatment choices they did or did not make for their family member. Patients and families need to be aware of the treatment choices available to them and their dying loved one. They need to be informed fully of the anticipated outcome of those strategies and understand their right to *refuse* any treatments. Families of the patient need complete information at the time of the health crisis for informed decisions to occur. This is no easy task.

Death education for dying patients and their families is of critical importance for the provision of a quality Palliative Care program. Health professionals need to work with

terminally ill and chronically ill patients and their families to identify the family members personal understanding of death thereby clarifying misconceptions and providing on-going support throughout the dying process.

In my experience in geriatrics and palliative care, I have yet to hear a patient or family member describe their interpretation of a “good death” as that identified by Post (cited in Matzo, 1997). His terms, such as “self-assessment,” “repentance,” or “rituals with family and friends,” have not been terms that I heard. Instead the more common words and phrases used are “with dignity,” “free of pain,” “peaceful,” and, “being with family or good friends.” Despite these variations in terminology, both researchers and families grapple with the concept of a good death, and regardless of the description, the key to planning and understanding the experience begins by determining what fosters a sense of hope and meaning in an individual’s life in such situations.

When my family discussed the Do-Not-Resuscitate order for Dad we used words that were *meaningful* to each other and to our father. We talked about what was important to Dad such as family, music, and his independence. *We considered how his life would change if he survived this crisis.* My mother, brothers, sisters, and I shared our recollections of Dad’s frequent comments concerning his fear of living with any type of mental or physical disability. And, we talked about our love for him and his love for each of us. From these discussions we made our decision.

Knowing that we fulfilled Dad’s final wishes erased my burden of doubt, and I felt that we were making the *right* decision. We experienced *no feelings* of guilt or regret of

which I know. Our father's own stories and our knowledge of what made his life meaningful guided the choice we made and support us in our grief of losing him.

In my professional life, I listened to grieving members struggle with the burden of making *end-of-life* treatment decisions for their dying elderly parents. Often these adult children already suffered with the grief of their loved one's impending death and at such an emotional time they were making treatment intervention decisions. Uninformed about their parents' dying wishes, this responsibility became a major factor in the dying process and later influenced the survivors' ability to grieve.

A common misconception of many family members is that all old people are ready to die and that their adult children are hopeful that death will happen soon. From my experience, both of these statements have more to do with relationships in families and quality of life than with the singular notion of age (Draper, 1992, p. 965).

I remember distinctly the emotional strife one family experienced throughout their elderly mother's lengthy dying process. During the admission process to the nursing home, family members informed me that their mother was old, 83, and was *waiting* to die since the death of her husband twenty years ago. *If something happened to her, death would be a blessing.* The words Do-Not-Resuscitate were never mentioned. They lowered their voices to a whisper as if to reveal a secret and said, *"If she gets sick we want nothing done. Just let her go, that is what she would want."*

Eventually, this lady became ill. Her entire family became distraught and frightened that she might die. The family members changed their minds about not wishing their mother resuscitated and were frantic pleading that she be transferred to the hospital to receive



intensive treatment intervention. This family relived this scenario several times during the final years of their mother's life. Finally, the physician intervened to explain the effects of repeated hospitalizations on their mother's diminishing quality of life and the family reconsidered the Do-Not-Resuscitate order. Three weeks later they stood at her bedside to comfort her as she died. Because of their inability to understand the dying process, they felt guilty about putting their mother through so much additional suffering. Regret filled their grief that lingered far beyond the time of her death.

When a parent is dying, the resulting grief is a *family experience*. Decisions whether or not to use life-prolonging treatment for a dying loved one is an agonizing experience for each member of the family and regardless of the type of treatment chosen, the thought of death remains constant. The persistent realization that life will never be the same again seeps into the consciousness of each family member and reality begins to shift and change. Families do whatever is necessary to survive the emotional pain and hold on to what comforted them in the past.

When we left the waiting room and entered Dad's hospital room, the atmosphere was suffocating and the silence was deafening. The fear of not knowing what to say created an awkward quiet. We were a family struggling to connect and to feel comfortable and safe with each other. Each of us arrived at our father's bedside frightened and our fear was exhausting. Although we wanted to stay close to Dad, we agonized over the thought of his death. We kept glancing at Dad from time to time while we spoke softly about trivialities.

My brother Donald, sat close to Dad and touched his motionless hand and spoke to him "*You always had great hands. Your fingers are in better shape than mine. It must have*

*been all that banjo and piano playing.” Donald continued to stroke Dad’s hand where he noticed the tip of Dad’s middle finger of his left hand. The bone must have been broken at one time and never healed properly. Donald teased with Dad “Oh Yeah! I remember you telling me about this. You did this playing baseball when you were just a kid.” Donald remained sitting close to Dad. He touched him and spoke to him, half anticipating a response although he knew he would never hear one.*

*If an outsider observed us with no knowledge of the decision our family just made, nothing would appear changed. Donald was still a son sitting beside his elderly father enjoying the close, loving relationship they always shared. Oxygen, fluids and medication still flowed through the maze of interconnected clear coloured tubing inserted into Dad’s veins. Our family was still intact. Dad was still with us and we focused on his living rather than on his dying.*

*As a nurse with a special interest in the care of the dying, I often discussed the issue of end-of-life treatment interventions with patients, families, and other nurses. As a result of these discussions I became aware of the amount of misinformation, confusion, and apprehension associated with this topic, specifically that relating to withholding resuscitation.*

*Not all patients or families choose the Do-Not-Resuscitate treatment option. When the choice involves the end-of-life care of a loved one, the magnitude of this personal and complex moral decision is overwhelming. Improved public awareness of treatment options available will better support dying patients and their families. Such support is very necessary*

and without more understanding of the death and dying process, anxiety, confusion, and misinterpretation of what withholding resuscitation means will persist. Such confusion and misinterpretation will complicate the grief of the survivors.

Even as a member of the medical community, I was overwhelmed by anxiety and emotions on the night I used my experience as a nurse to help my family understand the choice we made. *Withholding resuscitation did not imply the withholding of supportive care and treatment, including palliative care for our father.* Dad continued to receive fluids, oxygen and medication to keep him comfortable. There was no significant change in the care he received. The important difference would come when his heart stopped. There would be no treatment to intervene and he would die.

Like other families which I professionally interacted with, my family gained comfort by knowing Dad would continue to receive treatment and that he was *not* just left to die.

During my father's final days in hospital he remained unconscious. His family never ignored his presence nor was he removed from our conversations. He was not "put away in advance in the dead man's room" (de Certeau, 1984, p. 190). He was not surrounded by silence and denial. My mother, brothers, and sisters all knew that Dad was dying. With the issue of withholding resuscitation agreed upon, we settled and focused on his living and on the time we had left to be together. As a family, "our quiet waiting" (Faifel, 1977, p. 138) had begun.

Personal Reflections - December 17, 1996: The Waiting Begins

Almost midnight and with visiting hours over long ago, the corridors were empty. Only families like ours remained. They were the other grieving loved ones for whom the visiting hours and bells meant nothing.

Our father's impending death granted my brothers and sisters an implied special status permitting us to stay with Dad. Outside his small private room, the muffled sounds of nurses' voices calling out the names of patients according to room number offered the indication of human activity in an otherwise silent corridor. Within the hospital's organization with its continuous rules and procedures, the significance of a single human life, death and the needs of a grieving family were being valued by the health care staff.

In the structured and regulated temporal order (Fox, 1989) of the late shift, the purposeful dimming of the lights above the corridor created the perception of a *theatrical tranquility* that had little to do with the reality that existed behind the patient's half closed doors where the lives of patients and families were being *forever* changed.

My brother and sisters were exhausted; Jane and Lisa sat in silence. It was difficult for Donald to stay awake, as he sat with his arms folded across Dad's bed-rail, resting his chin against them. Talking in whispers our words filled with grief and fatigue. My family began visiting the hospital December 13<sup>th</sup> when Dad was admitted and their vigil was now into the fourth day. Jane's eyes filled with tears as she stroked Dad's hair. Looking at his handsome face, she asked me "*Sandra, if Dad's right side is paralyzed, where was the stroke? What side of his brain?*" I explained "*the opposite side.*" Jane listened and

continued to touch Dad's face and hair and talk to him — "*what a beautiful face you have.*" Jane's usual confidence was gone. Her voice was filled with fatigue and sorrow. Opening his weary eyes Donald mumbled that he would leave, that he was tired.

When hope for recovery is no longer possible, grieving family members are confronted with the inevitability of death. Waiting and watching a loved one die becomes a test of endurance, an overwhelming experience of loss that challenges those who grieve at every level of their being. The resulting depletion of the bereaved loved one's emotional resources and time, place them at increased risk for physical illness and depression. Their need to receive compassionate, comprehensive grief support is paramount.

Health professionals have the knowledge and skills to assess health issues related to grief and are well positioned to provide the information and encouragement needed to help people cope. Physicians and nurses who work with grieving patients and their families must be sensitive and diligent in their attempts to support the unique dying and death needs inherent in all clients.

As a nurse, I pride myself on my ability to assess the physical and emotional needs of my patients and their families. I agree with Nightingale (1859) that "acute observation" (p. vii) is critical to the roles and responsibilities of all nurses and that the ability to watch and to make appropriate decisions based on what is viewed is essential when caring for dying patients and their loved ones. Feelings of loss may be difficult to express and for many people emotions associated with grief are easier to demonstrate-through tears and hand wringing-than to verbalize. When health professionals *are* successful in establishing close

relationships with dying patients and their grieving families, they are better able to understand the unique needs of those who are grieving.

Most experienced health care providers admit that patients and their families are more aware of their needs than anyone else. When encouraged to share with health care professionals the pertinent physical, emotional, social, and spiritual information about their loved one, family members provide unique and arcane insight into the dying and death needs particular to that patient. When dying patients and their grieving families participate more in decision making regardless of the medical outcome, they often perceive their relationships with health professionals as significant, positive, supportive factors in their ongoing grieving process.

The challenges associated with impending death and feelings of persistent fear and uncertainty can overwhelm and demoralize grieving family members. The intense complexity of these emotions erodes their sense of stability and they are immobilized by their own feelings of intense vulnerability.

In my experiences I learned that any degree of grief support and comfort I can provide to those involved, is dependent upon identifying what losses have been experienced and which of those losses caused the greatest sense of grief. With my father ill, it was now time to do this for my own family. *I began preparing for what lay ahead as no health professional knew my family better than I did. I realized what was necessary to support and comfort my loved ones in their grief.*

Working as a Palliative Care Volunteer, I saw how different grieving families care for each other when crisis disrupts their lives. The strength of their mutual ability to support

and care for their loved-ones stems from their familiarity and knowledge of each other's coping behaviors and their common interest in caring for someone they love. Grieving families are left with an increased sense of vulnerability and isolation while they struggle to do the best they can by utilizing their familiar coping strategies that have supported them in past crisis.

According to Frank (1995) this mutuality of need, occurs when people have the desire or need to care for each other (p. 25). This particular need arises when a sudden crisis occurs and those involved are too overwhelmed by their own unfamiliar and uncontrollable emotions to care for others, when they also are needing care.

This need to care for each other does not always happen, nor does it always happen easily. Not all families are comfortable showing their emotions and privacy is essential. Looking at the tired expressions of my brother and sisters, I knew that they needed privacy to regain control in the midst of the chaos that surrounded them.

I explained to my family that I was going to speak with the nurses and let them know I was staying in the room with Dad. I walked down the stark, faded yellow corridor and introduced myself to the nurses working over stacks of patient charts and used my maiden name so they could make the connection with Dad "*I'm Sandra Hall. I'm Lorne Hall's daughter.*" I asked the nurses for a family only card to put on Dad's door. I explained how we wanted to stop visitors from walking into his room, that Dad would be uncomfortable with non-family members seeing him in his weakened state.

Returning to Dad's room, I taped the notice to the outside of the heavy wooden door, and stepped back inside explaining "*Nobody gets through that door unless we want*

*them in here. Dad is well known in town and as soon as the word get around what has happened to him everyone and their dog will be coming in to gape at him."*

For our grieving family's *new reality* this tiny hospital room was the extension of our home until Dad died. *The card on the door staked-out our family's territory and drew the property lines between public and private, between everyone else and us.* Without the permission of anyone *inside*, no one was welcome. These were the last days of our Dad's life. We needed the freedom to share our thoughts and our emotions with *only family* without anticipating interruptions. The simple power of keeping strangers out of Dad's room was the constant control we had while grieving the loss of our father.

For a dying patient and grieving families, privacy is an important issue. Though palliative care is a concept or system — a type of caring (as opposed to a place), special consideration is necessary when addressing the needs of those in a palliative situation. Privacy can be the essential component that creates the right atmosphere or environment for dying and death. This challenges Hayes (1996) suggestion "there is no right place to die" (p. 27).

In geriatric and palliative care the benefit of providing patients and grieving families with privacy is tangible. Behind closed doors, dying patients and loved ones struggle to re-establish a sense of normalcy in their lives by relating to each other in ways most familiar and comforting to them. Single occupancy rooms create a secluded environment within the hospital that encourage patients and families to express their concerns and communicate grief emotions in a manner that a double occupancy room cannot. The benefit of this



secluded environment was identified to me as a nurse by many dying patients and their families as the *most important factor* that contributed to their loved one's *quality of life during their dying process*. *Privacy also had effectiveness when pain control was an issue.*

In 1985, a friend of mine was diagnosed with a terminal illness. Her excruciating pain required frequent hospital admissions that diminished her ability to live her life in ways that were meaningful to her.

During one of my visits to the hospital, she felt awkward confiding how her discomfort was lessened only by her husband lying in bed and holding her. The comfort of his embrace helped her relax and enhanced the effect of her pain medication. She was grateful for the private room that gave her the feeling of being *at home* and being herself.

The home-like environment of the private room gave my dying friend the opportunity to share intimate conversations with her husband and loved ones without concern for other patients. The private hospital room was an extension of her home where she continued living her life much like she always did until she died. The memories of her final days and the private times they shared together in the private hospital room now support her grieving family.

As a grieving daughter, I needed to create the same supportive palliative care environment for my family. I wanted my mother, brothers, and sisters to remember Dad's dying in this room as a comforting grief memory. I also needed the privacy. The final days I spent alone with Dad in the privacy of his room are comforting memories of his peaceful dying.

Looking at the clock on the wall I tried taking care of my exhausted family. It was 1:00 a.m., and I suggested my brother and sisters go home and get some rest. Unlike me, their vigil with Dad began December 13<sup>th</sup>, four long days ago. Donald, Jane and Lisa bundled up their jackets. All three of them kissed Dad goodnight and said “*I love you*” to his sleeping face and within moments it was just Dad and me.

On that first night when my two sisters and my brother left to go home, no one mentioned that I should go home with them. They each kissed me goodnight and said that they were glad I was here. Without saying the words they already knew I was where I needed to be. As a family we understood each other’s need to do whatever it was to get us through these days. Right now being with Dad gave me peace and by being with him I was doing what I needed to do. My father’s dying was the emotional component that brought together “the dynamics of separation and reunion” (Becker & Mangolin, cited in Faifel, 1996, p. 24). *For years I prayed to be with Dad when he died. My prayers were answered.*

After my brother and sisters left Dad’s room I settled in and became more familiar with this new environment. I walked around Dad’s room opening the dresser drawers trying to feel more comfortable. I knew my father would die in this room, and I wanted to be more aware of these surroundings. How long I would be here was uncertain. Leaving was never considered. I prepared to stay with Dad until he died.

Much of what I saw in Dad’s room was familiar for me. From my perspective as a nurse I saw nothing unusual about the surroundings until I opened the narrow door to a small wood trimmed closet and saw my father’s street clothes. Suddenly my perspective as a

nurse disappeared and I stood with the sensibilities of Dad's daughter staring at the familiar shapes and colours of my father's clothes.

Seeing Dad's clothing overwhelmed my heart and filled my head with flashes of memory. I felt like an intruder eavesdropping on things that were not mine. I glanced over my shoulder and looked at Dad as if to ask permission. I touched the sleeve of the beige coloured jacket and moved it aside on the metal hanger. I smiled, seeing Dad's favourite old sweater folded over his well-worn trousers. A gentle yet hurtful thought illuminated this reality: *these are the clothes Dad wore when he dressed himself on the morning of December 13<sup>th</sup> before being admitted to the hospital. This is how he looked when he left home for the last time.*

I cried imagining the harshest truth. Dad will never wear these clothes again. He is dying. I pressed my face into his jacket filling my senses with the familiar smell (Howes, 1991) that was *only* Dad's.

Overwhelmed by the sight of my father's clothes hanging lifeless and empty, I closed the closet door. The sensuality and intensity of my grief was tactile. Little traces of Dad's essence clung to the fibers of his clothes like fragile memories and shattered my emotions.

There is a *unique* grief experience associated with the clothing of dying or dead loved-ones. Not often discussed or well documented by academics, this grief phenomenon is familiar to those who grieve the loss of a loved one. This experience is also common in geriatric and palliative care where resulting emotions reflect a deep connection between grieving loved ones and the significant relationship to the personal essence of the deceased.

Howes (1991) emphasizes this experience by explaining at the psychological level scents “cause changes in us” (p. 132). We are transported by the memory of a familiar smell and logical reasoning is obstructed.

During my nursing experience in long term and palliative care, I witnessed the emotional pain of grieving families when removing the personal belongings of their deceased loved one. Taking home their dead loved one’s clothing caused deep emotional distress. Families left these belongings in the storage department intending to collect them at a future date and never returned. The task of losing someone they loved and needing to deal with the retrieval of such personal and private belongings at the same time was too overwhelming for many families.

Recently a friend spoke to me about her grief experience following the death of her mother. Timidly she described how she keeps her mother’s favourite blouse hanging in the closet next to her own. This comforts her and helps her feel close to her mother.

My friend’s shyness disappeared when I explained how I also keep two of my father’s undershirts and one of his white pharmacy jackets and that following Dad’s I death wore his undershirts to feel his closeness. I shared with her how my brothers and sisters also keep articles of our father’s clothing and that three years after his death, our mother has not yet disposed of Dad’s personal belongings. I explained to her that this does not concern me because I believe Mom will make necessary grieving decisions in her own time, in her own way.

I thought about my mother, my brothers, and sisters and how I would approach their need to take Dad's clothing home. With my experience as a nurse and my knowledge of my family, I could not image how they would feel leaving the hospital clutching Dad's shoes and his clothing after he died. The emptiness of such a hurtful task would be heartbreaking and I wanted to protect my family from this experience.

I decided to watch and wait for an opportune time to speak to my brothers and sisters about Dad's personal belongings and suggest they consider removing them gradually rather than taking them all at once. I was aware the removal of Dad's belongings before he died might be interpreted by my family as giving-up hope. I had to shift my family's previous desire for hope for life to a shared hope of him dying peacefully.

On that night, I slept on Dad's bed alongside him. I felt peaceful. The *hellish relentless anxiety of anticipatory grief disappeared*. After five years of living in fear of Dad dying, I waited for his death feeling a deep sense of harmony with his leaving similar to that described by Redfield (1993). I felt destined, as though our lives had been guided by some unexplained force. I prayed to God to be here when Dad died. There was no where else I wanted to be.

Glancing at my watch, I realized it was later than I thought. The *changing over* of the day staff to the night staff signified the transference of responsibilities from one team of nurses to another. Organized shifts defined the time when the environmental characteristics of the hospital altered and each eight hour or twelve hour shift reflected the cultural, social, technical, and practical nature of the institution unique to that period. In a hospital, all

procedures and tasks are planned and scheduled to occur within a specific time, during a predetermined shift, when the ratio between staff member and patient is sufficient. In an environment where crisis is common, order and consistency are used to eliminate the majority of unplanned and unusual occurrences. I expected Dad's nurses to be upset when they saw me lying on his bed but they said nothing.

One of the cardinal rules in my basic nursing education emphasized a patient's bed as a unique space designated for the patient. Cleanliness and patient safety were paramount. Nothing was to be placed on the bed such as visitors handbags or coats and no one was ever to lay on the bed other than the patient and no one was to lay on the bed with the patient. This rule was well enforced and nurses spoke to wrongdoers about their unacceptable bed behavior whenever necessary. The attitude about patients' beds has changed over the years, but I still remember the first time I witnessed support for unacceptable bed behavior.

I was in my third year of nurse's training and working the night shift, when I noticed a man lying on the bed beside a four year old girl. On my way to the nurse's station to inquire about this incident, I met a nurse who helped me understand why this man was allowed to do this.

The little girl had been playing in her driveway when her father moved his truck and drove over her. She sustained head injuries and was in a coma. It was her father I saw lying beside her. He visited every night and slept beside her. He held her in his arms and whispered songs and stories in her ear. This continued until she regained consciousness a month later. Her physician referred to her recovery as a *miracle of love through the caring*

*that her father had given her and that the power of love and comfort could work miracles beyond understanding.*

As I laid by my Dad throughout the night, nurses came and went as they did their rounds and many times smiled, seeing me lying beside him and asked if I needed anything. My answer was always the same *“No thanks, I have all I need right here. As long as I can be close to Dad, I don't need anything else.”*

The nurses became familiar with my staying with Dad and they would come in the room to tell me they just made a fresh pot of coffee in their lounge and that I was welcome to have some. I was comforted by their attention to both Dad and me. I also felt unconcerned about my ability to participate as a nurse in caring for my Dad. Their understanding of why I needed to be with Dad, made it possible for me to communicate with them from my perspective of a concerned daughter with a nurse's insight into Dad's condition.

The collaborative attitude of the nurses made me feel welcomed and hopeful that my staying with Dad would be well received. In the past when Dad's nurses realized that I was also a nurse, my involvement in his care was problematic. The nurses avoided communicating with me about my father's care and my presence alone stifled any type of supportive interaction between my family and the registered nurses. *For twenty years this awkward situation affected the quality of care my Dad and my family had received.*

There is a common assumption that having a registered nurse as a member of the family to be an unquestionable benefit when a health crisis occurs. The reality is a far less

reliable advantage than might be anticipated; and may even be perceived as a detriment. The insight that might be gained through the collaboration with the nurse/family member is often unwelcomed. Often the situation evolves into a *nightmarish maze* constructed by the health professionals with walls of silence, power, and intimidation. The presence of a nurse at the bedside of her loved-one creates a situation for other health care providers to encourage or discourage the involvement of that specific family with their unique knowledge perspective.

Nurses who are also daughters, sisters, mothers, and wives, sometimes chose to not mention their professional identity when a family member experiences a medical crisis. The most common reason nurses give in support of this practice is that it is their attempt to avoid creating problems associated with the perception of overlapping roles and responsibilities and of appearing to be interfering with the on staff health care providers.

This “them-or-us” mind-set is most evident in the organized culture of the active treatment hospital that continues to protect and promote the entrenched hierarchal authoritative structure where the physician is the supreme authority. Not unlike a game — whereby different players chose different strategies in order to achieve their goal — individual nurses select specific methods to manoeuver themselves within their own families health crisis situation. Throughout the years of Dad’s chronic heart problems, I chose to be involved wherever and whenever I could because Dad and I shared a relationship that encouraged my involvement. Mom often thanked me for being such a help and my brothers and sisters never questioned my need to participate for they too were involved.

It was Dad who was ill, but we were the family who loved him and we were also the ones who knew him best. As one of Dad’s five children and a nurse, I knew that this



combination of information was valuable, and that it would help the staff who cared for Dad to see him as the individual he was.

After years of struggling to obtain and maintain this reciprocal flow of information and personalized care for my elderly father and compassionate support and understanding for my grieving mother, my brothers and sisters, the situation I hoped to achieve, happened. My relationship with my father was considered helpful and Dad's physician and the nurses were appreciative of my involvement in his care. They valued my insight as a nurse and a daughter and we all worked well together. With such support from Dad's healthcare providers, I could focus all of my attention and energy on the needs of my dying father and my grieving family. After what felt like a lifetime of anxiety living in the private hell of anticipatory grief, I felt complete peace and tranquility.

Personal Reflections - December 18, 1996: Family Gathering

Aside from the dim light at the head of Dad's bed, the room was still dark when the night nurse came in to make her final rounds before going off duty. We spoke and agreed Dad appeared to be comfortable and there was no change in his condition since yesterday. Dad's nurse asked how my family were feeling and suggested I get some rest. She told me she worked again that night, smiled and was gone. Again Dad and I were alone.

Without the visits from the nurses marking the beginning and end of their shifts, I had no idea when one day ended and the other began. The time of day was irrelevant to me. Without concentrating I could not remember the date. Inside Dad's room the passage of hours and days overlapped uninterrupted by periods of routine medical treatment and procedures.

Dad's physician visited on his morning rounds, checked Dad's blood pressure and pulse and listened to his lungs for any sign of fluid caused by his congestive heart failure. He inquired about my mother, brothers, and sisters. Referring to the Do Not Resuscitate decision my family made last evening, he inquired if we were *still okay* with the choice we made. I explained *we were, and that we loved Dad too much to make any other decision. We knew what he would have wanted if he had been able to speak for himself.* The doctor touched Dad's shoulder and smiled reminiscing about their doctor/patient relationship, *"Lorne was quite entertaining. He could also be quite creative with his medications if you didn't watch him."* He continued with his story and laughed, *"your dad always booked the last appointment of the day. He wanted to avoid the full waiting room. Too many germs!"* We both laughed. Before leaving he commented, *"Your Dad seems comfortable."*

When Dad's physician visited, I saw again some of the same relationship I witnessed between him and my father the previous year when I accompanied Dad on one of his doctor's appointments. The doctor and Dad liked each other. He took his time with Dad and listened to his stories. Dad appreciated this and often explained to me *"He's smart. He takes his time and he thinks everything through. I think you'd like him. Someday I'm going to take my banjo down to his office and play him a tune."*

My father was fortunate because the relationship he had with his physician was out of the ordinary. It is more common for my elderly patients to complain their doctors rush through their appointments and never listen to them. These problems associated with doctor/patient relationships become more complex when other family members were involved.

During my years of nursing elderly and dying patients, it was often necessary for me to mediate between grieving family members and their loved one's physicians. When medical problems occurred and treatment decisions needed to be made in a crisis, the situation became difficult when family members and physicians had never met and knew nothing about each other. More important, they had never discussed the patient. It was not uncommon for the physician and the family member to support opposing philosophies regarding end of life medical care and treatment.

When a crisis occurred the differences in opinion between the physician and family member distracted productive time and energy away from the treatment issues concerning the patient. Without meaningful intervention by a nurse between physicians and grieving next of kin, the situation deteriorated. Communications stopped and the patient's death occurred in an atmosphere of anger and frustration. These upsetting experiences endure and become a significant grief memory associated with a loved one's death.

Through the vicarious perspective of a health professional, I witnessed problematic relationships between physicians and family members. While my professional experience was guiding me as Dad's daughter this additional insight into the relationship between the physician and a patient and his/her family was disconcerting.

Over the years, Dad had several different doctors attend to his health. During that time, some doctors were reluctant to communicate with me, while others appeared comfortable with my involvement in Dad's care. A few avoided me whenever I started talking like a nurse. One physician refused to communicate with me on any level and ignored

any assistance I offered based on my awareness as Dad's daughter and my background as a geriatric nurse.

The situation with this particular physician became intolerable and over time he cut-off the entire family from any form of communication. We were separated from any information regarding Dad's condition or treatment and we were never made to feel a part of what was happening to our father. It was my presence and my inquiries that created the most problems when it became apparent that my being a nurse was complicating a frightening experience for my entire family. Along with the fear and concern that I felt for Dad's well-being, I was exhausted by the psychological stress of trying to avoid being manipulated by the health care bureaucracy or by trying to manipulate the system myself. The constant haggling was time consuming and distracted from the time that I could just sit with Dad and be his daughter.

My mother, brothers, and sisters relied on my professional understanding of Dad's heart condition and my familiarity with the hospital protocol regarding procedures and equipment to help them through difficult times. My alienation by Dad's physician forced me into a situation where I was unable to help the people I loved most.

However, Dad's present doctor had an interest in, as well as compassion, and concern for Dad and for our family. His compassionate attitude comforted all of us through time of extreme emotion and sensitivity. He answered our questions and eased our concerns. He valued our family's need to be informed about Dad's stroke and to be involved in his care. He also understood and respected our desire to be with Dad during his final days.

This was a different and welcome experience for me. The caring relationship between our dying father, his physician and our family lessened my worries as a nurse and as a daughter, leaving me free to focus on Dad and my family.

When Dad's physician accepted me as part of my father's care team, it was a wonderful gift. He accepted my involvement and valued any information I offered about Dad. The physician's compassion for my dad and our family's experience lessened the fear and helplessness that filtered into our lives. As a grieving daughter, *"I became convinced that nothing the hospital could provide in the way of technological marvels was as helpful as an atmosphere of compassion"* (Cousins, 1980, p. 154).

Throughout the morning, the nurses moved in and out of Dad's room repositioning, checking, measuring, and recording his blood pressure, temperature, respirations, intravenous levels, and urinary output. Dad's "body was persistently under observation" (Fox, 1989, p. 152) by the staff as they performed their ritualistic rounds in an environment of continuous *purposeful* nursing care needs for my dad, a stroke victim.

Stroke patients require special nursing care considerations. Medications are often prescribed to stimulate respirations and circulation. Vital signs (temperature, pulse and respiratory rates) are observed for such complications as a rise in temperature, a slowing down of pulse or respirations, or a change in the patient's level of consciousness, all indicate a deepening of the coma and a poor prognosis. Mouth care is required every four hours with special attention needed for unconscious patients. A stroke paralyzes one side of the mouth and tongue increasing the patient's chance of choking. Patient's fluid levels are administered

through intravenous therapy and the amount of urine produced is measured and a lack of bowel control (fecal incontinence) is common.

Regular schedules for turning and repositioning patients are crucial in stroke care. Unconscious immobilized patients are in danger of the serious secondary complications of hypostatic pneumonia and circulatory status that causes death.

As a nurse I am familiar with the rituals and rules associated with patient care. My knowledge and understanding of the role and responsibilities of the nurse's duties eliminated any concerns I had about the care and treatment Dad received. I cared for patients like my father and I performed the same procedures. The environment was familiar. I moved into the routine of the hospital quite and I felt an "emotional equilibrium" (Faifel, 1977, p. 148).

With Dad now receiving care for his stroke, my family's grief moved into a type of slowing down period or "terminal phase" (Rolland, 1994, p. 49) in which death was inevitable and we had time to spend with Dad. My family had the opportunity to reflect on his time left to consider our feelings of death and separation, and to say our good-byes.

Grief is an individual journey influenced by many factors any time it relates to the death of a family member. One of the most significant factors influencing the individual's journey of grief is whether the loved one's death was anticipated or sudden.

As a nurse I spoke with grieving family members who had no desire to spend time with a dying loved-one. Observing the dying and death process was perceived as too hurtful for them to experience. One son could not visit his dying mother for the last five weeks of her life requested I notify him at the time of her death. When his mother died, her grieving

son came to the nursing home and sat at her bedside with her body for over one hour.

Crying, he explained that he needed to say good-bye to his mother but had to wait until it was over.

Other grieving family members shared stories of another type of grief experience when death occurred and the opportunity to spend time with a loved-one was impossible. Unlike my father's dying, the death in their family happened without warning leaving them to grieve with unresolved feelings. Years after the death, many still mourned the unrecognized or missed opportunity to talk with their loved one, to express their love, to apologize for a past disagreement, and to say their good-byes.

Not long ago, a woman spoke to me about the recent death of her father and identified yet another type of experience whereby she wanted more time with her dying father. She wanted this time not to apologize to him but to hear her father say he loved her. Unfortunately, her father died without saying these words and now her grieving focuses on her need to understand why he never said the words.

I grew up in a family where saying good-bye is a ritual. Whenever someone left to go on a major journey, an enthusiastic family wave from the livingroom window was a long standing tradition perpetuated by Dad. Depending on who was leaving, who was doing the waving, and how long the person would be gone; all created varying depths of emotions affecting the group wave. Without exception everyone in our family has been on the receiving end of this display of mutual affection that elicits anything from wails of unleashed laughter, to uncontrollable crying, and every emotional outburst in between.

Albeit that each member of my family has experienced the joy or the agony of this family ritual, none of us rejected the family wave until one day I felt I had no choice.

In September of 1996, six months before Dad died, I pleaded with my father to promise not to stand at the window and wave when I was leaving to return to Alberta. As I said my tearful goodbyes and drove away from the house, Dad had my family line up across the driveway and did the family wave. As far as Dad was concerned he did what I asked and kept his word not to stand and wave goodbye from the livingroom window. The last face I saw was Dad's as he raised his hand and waved "*goodbye Sanie — Daddy loves you.*"

That was the last time I saw Dad before I returned home to see him for the final time. I cherish the memory of my father waving goodbye and calling out that he loved me. My good-byes with Dad were never enough; I wanted to know there would be more and I feared for the time when they would end. When I anticipated how Dad would die, I considered the scenario where my final good-bye to him would happen. I wanted to remember our final time together as unhurried, peaceful, and loving. Whatever I anticipated might happen during Dad's final days, paled in comparison with the reality of what I experienced tonight sitting with my family and witnessing their individual expressions of good-bye.

Donald was sitting very close to Dad. He just finished telling a crazy story and laughed at his own storytelling. I was sitting and staring at Dad's face — straining to record every line, every subtle skin tone — I wanted to treasure it all. Donald laughed again. I noticed something happen and I prompted Donald to "*do that again, I think Dad's listening . . . quick do what you just did.*"



Donald repeated the story and Dad's lopsided smile revealed itself. As a nurse I first thought the movement might be a muscle reflex due to the stroke, but I hoped it wasn't. I needed to know. I was excited "*Donald do that one more time! Now everyone else watch!*" We all waited and the same thing happened again! We were thrilled! Donald tousled Dad's shoulder and laughed out loud and repeated the familiar affectionate phrase he used with him "*Hey Dad! You crazy ole bugger, you're laying there listening!*" The rest of the family were overjoyed. We laughed and Dad smiled again and we all knew that he was with us. Even in the midst of our anguish, this still was a wonderful evening and is now a cherished memory that we carry with us.

This evening was very special for my mother, brothers and sisters, in-laws and grandchildren. Tonight our entire family gathered around Dad's bed. We closed the door, we sat together, and we laughed often. This is when we are at our best — when we are telling stories together and laughing with Dad in the middle of it all — just where he has always been. In our grief of losing Dad we coped the only way we knew how.

In Palliative Care I often watch as families sit quietly at the bedside of a dying loved-one and notice variations in their need to be close. For some, the closeness is natural, for others it is brittle and awkward. Then, there are others who need to be given permission to stay close, to take down the bed-rail, and be reminded how important and comforting the touch of a loved-one can be to an ailing family member.

Our family had no problem with being close to Dad. Instead, our concern was the distance between us. Whether it was our need to care or our need to be cared-for, it was

unimportant. Each of us was grieving and we needed to feel secure. We needed to surround ourselves with the familiar closeness of our interactions.

In my nursing education the importance of communicating with patients regardless of their level of consciousness was emphasized by my instructors. All patients have a need to feel human contact either verbally or non-verbally and experience emotions associated with their relationships with others. When patients are dying the importance of knowing how to communicate with them throughout the dying process is essential. Communication becomes more significant for patients who experience some type of sensory disorder such as a stroke, or those who are close to dying.

Communicating with a loved-one you know is dying is often difficult, but very important. The dying process presents unique concerns that may interfere with the patient's ability to either be understood or to understand. Such concerns may include 1) medication induced drowsiness as the patient may be too sleepy to concentrate; 2) increased levels of pain or nausea which distracts concentration; 3) deteriorated condition with the patient sleeping the majority of the time; 4) neurologic impairment increases where the patient is unable to interact without direct stimulation, death is eminent, and the opportunity to communicate ends. This leaves the dying patient "censured, deprived of language, wrapped up in a shroud of silence" (de Certeau, 1984, p. 191).

Without effective communication both patients and family members may experience problems that increase their sense of loss when death occurs. Effective communication is vital to effective family coping with illness and disability (Rolland, 1994). Communication

defines the relationship that exists between the participants and reflects the feelings of those involved and even silence conveys an interpersonal message that each family and each individual family member has unique ways of communicating.

In order to understand the grief experience from the perspective of the family, a nurse must recognize the family's style of relating to each other when dealing with critical life problems. Familiarity with their problem-solving strategies is essential when attempting to gain a better understanding of their individual grief experience as it relates to chronic ill health and the unavoidable death of their loved one.

As a daughter I watched as my own family did what they felt was right when communicating with our father. From my experience with dying patients I encouraged my mother, brothers, and sisters to talk to Dad. I shared the teachings I learned as a nurse and explained that patients continue to hear when they can no longer speak and that even the dying hear right until the end.

My family listened and interacted with Dad as they always did. In family get-togethers of the past, laughter supported and comforted us. Similar to the work of Strickland (1996), we had a lot of laughter in the group, a lot of comforting silence and eye contact, as well as physical reaching out to one another by patting each other's hand or leg. These gestures were soothing.

Glancing around Dad's room at my mother, my brothers and sisters I thought of how very different their experience of Dad's stroke was from mine and how different we are from each other. We were five adult children ranging in age from thirty-one to forty-eight

and our sixty-eight year old mother. In the following days, our family came and went from this little room and then left and re-entered the other reality of their lives with their children and spouses. Our father's dying was layered on top of all the other responsibilities, worries and concerns that existed in our lives. I watched as my mother, brothers and sisters juggled their visits with Dad with other commitments in their multiple schedules. I watched to see how they coped with their grief and exhaustion. None of my family said they were having a problem handling everything that was happening, but their facial expressions often revealed more.

Grieving family members tend to over-look the grief experiences of siblings, as they too are grieving. This happens more often when a brother or sister does not complain or behave in a manner that suggests they were experiencing grief problems. Family members assume that there are no concerns and fail to look any further. Problems remain unaddressed and may lead to future inappropriate feelings of grief associated with regret and guilt.

In my family, our individual personalities as adult children became evident as Dad's health deteriorated. During the years of our father's chronic illness, my mother, brothers and sisters responded to his illnesses in very different ways. Some of my siblings reacted to the frequent crisis in our father's health by searching for solutions, and trying to fix what was wrong. Other members of the family appeared to accept the crisis as a fact of life. The variety of individual ways of problem solving and striving to achieve acceptable solutions to the problems created by Dad's health demonstrated my brothers and sisters and me to be as different as we were alike.

Being the nurse in the family, I found it interesting that through each health crisis the individual perceptions of my family members were never static. Whether the health crisis was viewed as life-threatening or another escalation of Dad's illness, family reactions varied.

Through years of nursing experience, I became familiar with the professional responsibilities involved in providing information to families and patients about patient's medical condition and treatment. I realized that not everyone accepted or received information in the same manner and when I answered my family's questions about the hospital equipment and procedures I realized my family were like any other family.

The subtle changes in my family's emotional responses were influenced by the amount of information my individual brothers and sisters were given and how much they understood of what was happening with our dad. The influence of our father's past health crises was also reflected in our individual responses. Throughout these prior setbacks, my family either benefitted from the learning or was more frightened and overwhelmed by the worsening events. In either positive or negative ways, families responded to multiple health crises, and repeated cycles of good, fair and poor health status. Learning about family members as individuals and about each individual's role as a member of the family, as a collective, are crucial when attempting to recognize and understand different types of grief behaviors.

During the last eight years volunteering in a palliative care unit in my community, I was surprised by the different ways grieving family members relate to the inevitable death of

a loved one. Some visitors seem restless when visiting and pace back and forth rather than sit. These visitors persist on asking the nurses to contact the physician to check if there was more that could be done. These visitors spent limited time at the bedside communicating with their dying loved one and appear agitated and lost. Because of this behavior, neither the dying patient nor the grieving family member seems to receive the closeness or sense of comfort they need in the final days before death occurs.

Opposite from these restless family visitors are those who spend all their time at the bedside speaking, listening, and touching their dying loved one. Such family members appear to achieve a sense of peace with the impending death. They are able to share the remaining time supporting their loved one by furthering the relationship and encouraging a peaceful, loving environment until the end.

As a nurse I learned many things from my patients and their families. Not long ago, an important truth about anticipatory grief was revealed to me. A tearful grieving husband who was visiting his young, dying wife in palliative care described to me the importance of being present at the bedside of the dying. Emotions overwhelmed his words as he explained how he spent thousands of dollars and hours upon hours searching for a cure for his wife. He described his regret for not having accepted his wife's death as a certainty earlier. Shaking his head he described his relentless investigation for a cure as a waste of precious time that took him away from his dying wife. He spoke quietly, *"I wasted so much time, even when I was here I kept talking about cures."* He hesitated . . . *"I should have been talking to her about our family, about our kids. She needed to hear that I loved her."*

From this man's experience I knew that I too had to settle down and be present at Dad's bedside for myself, for my family and most of all for my father. I needed to move beyond what it meant to be a nurse, a friend, or a daughter and connect with Dad on a human level. This was not a call for *doing for* care but a call for *being with* care; this is care that incorporates differences among individuals and among situations. "One can never understand the experience of another" (McIntyre, 1997 p. 25). As Dad's daughter I wanted to cherish these final days. I also wanted my family to associate Dad's dying with memories of peace rather than chaos.

When a death occurs in a family, feelings of grief, the uncertainties of living with traumatic changes, and emotional exhaustion tend to magnify family differences rather than similarities. Somewhat, my limited perspective based on my own close relationship with Dad valued my grief over my siblings. I failed to recognize their association with Dad as being equal to mine. In the past smaller, less significant family problems did not emphasize these differences, whereas my family's major grief experience with our father's death did.

In my work as a nurse, I supported grieving family members through their different grief experiences. During these times individual family members came to me to promote the value of *their* relationship to their dying loved one as being more significant than that of the other siblings. These conversations occurred in private, away from their siblings, and separate from anyone with the knowledge to challenge the validity of what they were saying. Their comments were never mean-spirited or aggressive toward their siblings, but their intent was clear. For whatever reason these family members needed to identify the

uniqueness of their grief experience as being different and more significant than other family members.

This experience occurs more often when grieving family members have unresolved interpersonal issues with other siblings or when a family member lives away from their larger family unit. Distance affects their ability to participate in their family's grief experience in a shared and similar manner. Secretive conversations are their attempt to identify their role in their family, clarify reasons for their previous absence and current involvement at the bedside, and emphasize their relationship to their dying loved one. The issue of geographical distance from their family's grief experience influences their attitude and behavior within the dying and death process.

Since moving to Alberta in 1988, I became the *one-from-away* in my family. I am the only member of my family that lives a long distance from my extended family. Being back home and in the hospital with my dying father, along with my mother, brothers and sisters filled me with unanticipated emotions.

As a daughter and a sister I needed to catch-up with my family and their grief experience. I wanted to know what they knew. I wanted to hear the details of what happened to Dad before I arrived. Returning home in mid-crisis, I felt an accelerated need to move through the events of my family's experiences of the days prior to Dad's stroke in order to cope with my present.

Before my identity became the family member from away, I, like many of my nursing colleagues, considered such relatives like me as additional problems who further complicated a dubious family crisis. Working with these relatives I often focused on their



argumentative, quarrelsome, overall troublesome behavior. All too often I failed to take the time to understand the basis of their particular response to the health crisis.

With the insight I gained from my experience as the from-away family member, I have a new understanding of this unique anticipatory grief experience. I now empathize with the perspective of these individuals and I believe that health professionals need to re-evaluate their assumptions regarding these family members. Nurses must see the importance of establishing supportive relationships with these grieving relatives and assist them throughout this experience.

The number of these relatives from- away will increase as fundamental changes in the structure of kinship ties within the contemporary family occur (Kesterton, 1995). When adult children move away from their families in order to seek employment opportunities, their family bonds change. It is therefore reasonable that the from-away response to impending death be further studied and better understood. This unique familial grief experience is grouped together as part of the family grief experience and by doing so loses some of the special consideration that this particular dying and death perspective requires.

Sitting in Dad's hospital room listening and watching my mother, brothers and sisters, I became more comfortable in the aftermath of Dad's latest health crisis. Gradually I began to focus on the reality that regardless of how far away I live from those I loved that this is still my family, their pain is my pain.

Since Dad's death I gained a sensitive awareness of how different the relationships are between individual family members and their parents. I assumed a high degree of

similarity between my brothers and sisters in how we needed to grieve. But I was wrong and I now perceive family grief as a tree with out-reaching branches. While the branches grow from a common trunk, the individual limbs seek the sun in different ways. I realized that in my own close family, each of my brothers and sisters experienced a relationship with Dad that differed from mine in various ways and at times it seemed as if we were mourning the loss of a different person, a different father and for one, a husband.

In geriatric and palliative care nursing, I was familiar with many widowed elderly women who shared with me the memories of their husbands' deaths and their passage into widowhood. These women talked about their complex grief emotions of loss after losing a longtime partner and their mourning feelings of anger, resentment, loneliness, and loss. The intensity of their grief memories and the experience of suffering such a significant loss late in their lives reflects what Shelley (1988) described as a loss "too profound for them to overcome at an advanced age" (p. 348).

As a nurse I responded to the needs of these grieving women. I spent time listening to them reminisce about their lives with their late husbands. I comforted them with a hug when they were overwhelmed by their cherished memories. As a health care professional, I was sensitive to the grieving needs of my widowed patients, while as a daughter I overlooked the grieving experience of my own mother. As the reality of widowhood crept into my mother's grief experience, I was comforting my brothers and sisters. I was humbled by my own insensitivity when I watched my mother sit next to Dad and say her final good-bye.

Mom stood quietly at Dad's bedside and rested her hand on his and whispered "*Poor Dad.*" Her words disappeared into silence as her tears washed away her voice. "*Good night dear. You have a good sleep. I love you.*" Mom spoke as if she knew that death would soon come to separate them. Mom kissed Dad again one last lingering time, and repeated "*I love you Lorne.*" Mom tried to hold back her tears, and shook her head, "*He wouldn't have wanted this. Even after all he's been through, I didn't think that he would die like this. It just breaks my heart. I can't stand to see him like this.*"

After forty-nine years of marriage, my mother was facing a profound change in her life. Alone.

In palliative and geriatric care I often met and spoke with widowed patients. Unless the death of their husband was recent, discussions concerning their widow's experience did not happen; their transition from being one-half of a couple to being alone was not considered a significant factor in their lives, but perceived as a natural phenomenon that older women experience. The very personal, complex interconnected issues associated with widowhood were often overlooked and devalued.

My mother's widowhood altered my perspective of this life-changing experience and increased my interest in understanding the extraordinary grief associated with the loss of a husband for an elderly woman. I knew my mother's life would change when my father died, but I did not consider to what degree. I focused on my own sense of loss and the grief needs of my siblings. While I did not overlook my mother's grieving needs I failed to recognize how different her needs were from mine and my brothers' and sisters.' As a nurse with

experience in palliative care. I took neither the time or the opportunity to consider the depth of my mother's loss and how much her life would be impacted by my father's death.

From my experience of staying home with Mom for a month following Dad's death, I gained insight into the implications grief and change had on her psychosocial wellness, lifestyle and health. As a nurse and a daughter I now have a better understanding of the variety of issues that may occur when the husband of an elderly woman dies. I also realize that health care professionals need to recognize this type of loss experience as causing "the greatest impact later in life" (Horman, 1989, p. 18) when the lives of many older women may already be compromised.

Over ten years ago, I sat listening to one of my elderly patient's share memories of her deceased husband and I was touched by her gentle recollections and what I learned as she removed old photographs and envelopes from her drawer. With tears in her eyes and defiance in her eighty-nine year old voice, she directed my attention to the envelopes she tossed on her bed "*Look at these! Look what they call me!*" she pointed at her name on the outside of the envelopes. "*Look! Right here! They never use Arthur's name. They use my first name instead! You'd think I was never married to him. As soon as my husband died his name disappeared from everything. Arthur's a nice name. I wish they would stop this!*" Later she showed me a beautiful old picture "*Here's my Arthur, wasn't he handsome? He had hair like a raven's wing and you could hide a new penny in mine.*"

This lady taught me a wonderful lesson about how we follow common everyday practices such as addressing a letter to a grieving widow in a particular way emphasizing the absent deceased husband. I remember this story well and whenever I mail a card or letter to

a widow, I follow this lady's advice. She taught me the importance of remembering even the smallest of grief related details and to value the grieving experiences of all individuals.

Further to this my father's death also taught me a lot about myself.

Not only did I misjudge my mother's grief needs, I also had little understanding of what was happening between my husband and me. Reading the comment by Strauss (cited in Rolland, 1994, p. 37) that fears about illness-related crises are often a major undercurrent of anxiety within a family, I nodded my head and acknowledged that I agreed.

When Gregg and I first discussed getting married, I asked if he was ready to always be the number two man in my life. That discussion was eleven years ago. When I said this to Gregg I knew what I was saying, but I knew nothing about what these words meant for my life as a married woman. As far as Gregg was concerned, he had no way of knowing how the complications of the chronic ill-health of his soon to be seventy-one year old father-in-law would impact his life and our relationship together as husband and wife.

Not long after we married Dad's health started to deteriorate and I became more and more frightened and concerned about what was happening. My taunting phrase referring to Dad's importance in my life loomed over both Gregg and me . . . and the marriage vows for better or worse were our reality.

When I married Gregg, I did not consider his lived-experiences or his family values or traditions. I certainly did not consider how Gregg or his family dealt with illness or death. We grew-up in the same small town and graduated together from the same high school. Heavens! Both of us were even plain old boring Protestants. Therefore, we had to be the same! From my perspective of a new first-time wife it was pretty simple, I love Gregg; we

have a lot in common; and I assumed that one of those commonalities would be the way we both deal with grief. To my surprise, these notions began to deteriorate.

The night I received the call informing me about Dad's stroke, the real differences between Gregg and me, and how we deal with the issues of illness and death revealed themselves. The differences in the way we both were enculturated within our families to respond to illness and dying separated us.

At one point of the intense night of December 16, I hated Gregg. I needed him to respond like me! I needed him to care about Dad as much as I did! Without question, I wanted him to think and act just like me and more than that, I needed it immediately! Anything less was unacceptable. Gregg saw the situation in a different way.

Gregg saw me as a terrified daughter charging around the house crying and acting irrational. I was not the same always under-control wife he married. He saw a stranger. But I saw something very different. I saw myself as a loving daughter and an informed nurse who was well aware of what happened to Dad and also of what was yet to come. Where Gregg saw illogical and out of control behavior, I felt an intense sense of purpose and energy to do what I needed to do.

There was no hope for Gregg and me to come together on that difficult night; he was responding with his logic and I was responding with mine; the two were irreconcilable. Gregg knew nothing about Dad and his stroke, and I knew more than most. We had no hope of reaching any understanding. There was none.

Gregg came home for Dad's funeral. Within hours of his arrival, he was involved with my family's grief process and trying his best to help out wherever he could. He did well being

surrounded by an entire household filled with exhausted, crying and confused family members that he knew for less than ten years and only saw once a year during each of those years.

Dad's funeral was difficult for the whole family. At the beginning of the service, Gregg held me and supported me as I walked on lifeless legs to the front of the church. Without him, I would have collapsed. Soon I realized that having Gregg home was almost as important for my mother as it was for me. Several times Mom commented how grateful she was to have all of her family home, and that Dad would have been proud we were all together. Mom considered Gregg part of our family and it was important to her to feel some sense of completeness in her *newly broken family*.

Gregg and I have come a long way in living together with my grief. These past three years has been a time of change and adjustment for both of us. When I reflect on the night of December 16, when I argued with Gregg to go home, to be with Dad, I see that it was a disaster waiting to happen. I made assumptions about my husband and his ability or even interest in dealing with this type of crisis from my perspective and that was wrong. Although we are alike in many ways, our beliefs and behaviors regarding illness and death are shaped by our different experiences and even our different professions of engineering and nursing contribute to our different perspectives.

I am the one who always emphasizes the importance of recognizing the differences between individuals and their responses to illness and death; therefore it is embarrassing to admit I was blind to the differences that existed between my husband and me. I realize I learned more about myself and the uniqueness of individual grief responses, by this painful

angry experience, than I would have if Gregg had been loving and supportive from the beginning.

The troublesome anticipatory grief differences between my husband and myself are not uncommon in geriatric and palliative care. In the past when I counselled couples in a similar situation, I took a quick dislike to the attitude of the argumentative husbands I met. Because of my distaste for their behavior I had limited interest in finding a way to help these individuals achieve a better understanding of their grief experience. My personal experience provided me with insight into why these differences occur, leaving me better prepared to offer *couples* positive support during their grief experience.

Personal Reflections - December 18, 1996: A Spiritual Comfort

It was three-thirty a.m. on my second night with Dad. I was lying beside him on his bed while a nurse checked his blood pressure. The room was quiet except for the squishing sound of the nurse compressing the small inflatable rubber bulb in her hand. I said nothing and stayed still while watching the ribbon of silver mercury climb inside the thin graduated glass tube. I felt something strange happening around me. I raised my head and looked at the nurse. *"Wow! Did you feel that?"* She nodded her head and whispered *"no"* and rechecked Dad's blood pressure. Still amazed and excited by what happened and I continued talking *"Wow! You mean you didn't feel that? That was the strangest thing I have ever felt!"* Dad's nurse listened as I tried to put into words what I experienced.

*"Lord that was amazing! I felt it on my skin! It was a silence I could feel. It was peaceful and filled the whole room. I have never felt such a peace. It was all around me. The room was still. I heard a man's voice. I heard it and felt it at the same time. The voice*



*just said, 'He'll be okay' and it made me feel safe.* "I cuddled my head closer into Dad's neck and cried. The nurse touched my shoulder and asked if there was anything she could do. I shook my head *no* and she left Dad and I to be alone.

Stories of paranormal occurrences are not uncommon for health care professionals. I heard other nurses share stories of spiritual happenings with very ill patients but this encounter with Dad was my first. That night, I felt a new sense of inner peace and a unique sensation of quiet to have privileged sharing that moment with Dad.

The experience left me with a profound sense of security, in knowing that there are far greater things in this world than just those that can be measured, examined, and evaluated. As a health care professional, I work in an environment where anything that cannot be verified in some scientific manner is rejected. In my profession many would interpret my lack of sleep and sustained levels of heightened anxiety as explanations for what I experienced because the current health philosophy recognizes scientific principles. The paranormal is not validated.

According to Dossey, Keegan, Cuzzetta and Kolkmeier (1988) the separation between health care providers and patients is complicated by the changes that occurred during the late 19<sup>th</sup> and the first half of the 20<sup>th</sup> centuries. As the authors suggest, during this time an increased emphasis on specialization within the medical profession, combined with the increased division between doctors and nurses propelled the notion of healing the "whole body care" into the recesses of the past. The more specialized and technical the health care delivery system became, the less health care professionals considered the spiritual aspect of

care. By the 1960s, a few isolated physicians and nurses were interested in the importance of providing health care from a humanistic, holistic perspective. In contrast, the philosophy underlying science reflected the “disgoddling” of nature as expressed by the German poet Schiller (cited in Dossey et al., 1988), and the notion of the “mind-body split” as proposed by the 17<sup>th</sup> Century philosopher Descartes.

Influenced by this rationalist philosophy, most physicians and nurses work painstakingly at providing care to the sick by utilizing their best atomistic approaches within a scientific framework. Nurses educated within religious communities continued to integrate a spiritual approach to their nursing care practice, strengthened by the teachings of the Christian medieval scholar Thomas Aquinas (cited in Dossey et al. 1988), who emphasized the body and spirit as inseparable.

In the article entitled Unsung Heroes, (Golden, Jaroff, Kluger & Lemonick, 1999) Swiss born psychiatrist Elisabeth Kubler-Ross is described as causing distress in the psychiatric community because of her current infatuation with the afterlife and mysticism. Although her work bears much respect, critics judge her interest in the paranormal as unacceptable. These criticisms indicate that medicine continues its reluctance to value the contribution of any philosophy that cannot be measured, categorized or replicated, and criticizes those who do.

A holistic, integrated family patient care model is the philosophy I learned during my basic nursing education from a school of nursing where the fundamentals of a Christian philosophy promoted more than the science of health care. The values of St. Martha’s School of Nursing guided my nursing education and influence how I interact with dying patients and

grieving families. This philosophy, in combination with my years spent in geriatric and palliative care, influenced the type of family-focused, holistic care my father received when he died.

Stories of paranormal occurrences are not uncommon to me. My mother and father were both intuitive and discussions involving this special way of perceiving the world around us were considered quite ordinary. As a teenager, I remember Dad teasing Mom with *“Mother, you must be some kind of witch! How do you know when something is going to happen?”* While at other times, Dad seemed to be quite intuitive himself.

In June of 1991, Dad did something unusual and phoned me. He started the conversation by asking *“If I was alright”*. His voice sounded concerned. His question confused me and I told him *“I was fine”* so I questioned him *“Why he asked.”* He hesitated, then explained *“Well Sanie, I was having a nap and I woke up and saw you standing beside my bed. You were dressed in your white nurse’s uniform.”* Dad’s words terrified me, but I tried not to let him know. I needed to ask more. to know more.

*“Dad, what did I look like?”* He answered as if I should have known, *“It was you Sanie! You had your hair tied up like you do when you are at work; and you just stood there — beside my bed and smiled. He then repeated — Yeah! It was you alright, you disappeared when I got up and walked toward you.”* Dad’s final comment frightened me.

Hearing Dad’s story I thought how much I resemble his dead mother and I assumed the image to be Nana’s. Many nurses would Dad’s vision of me standing at his bedside an omen preceding death. For generations nurses shared their stories of patient’s dying after they experienced seeing the image of a deceased loved-one standing at their bedside. Dad’s

experience was so unsettling to me that I explained my concern to Gregg and I made a special visit home to spend time with Dad. It later came as no real surprise to me that a few weeks after the dream occurred, Dad suffered his first heart attack. Such dreams like the one Dad shared with me are seldom taken lightly by nurses, including me.

Stories of mystical visitations and forerunners are validated in geriatric and palliative care. When a very ill or dying patient informs a staff member that they have seen a deceased loved-one at their bedside their comment is seldom ignored and nurses contact the patient's next of kin encouraging them to visit. Patients who are frightened by what they saw are comforted by the staff or (if requested) are visited by a member of the clergy. The information becomes important to all staff resulting in more frequent attention for that patient.

During my professional life in geriatric and palliative units, this type of mystical experience did occur and the patients involved died soon after. When I teach palliative care volunteers I inform them of this death-related phenomenon and emphasize the importance of reporting this incident to the nurse in charge as soon as possible. Anyone involved in palliative care needs to value or at least be aware of the different paranormal/spiritual experiences that may occur during the dying and death process and be prepared to assist patients and families who experience these events.

I heard my first death-bed ghost story in 1968, just months after starting nursing school. I was working with a senior nurse who told me to pay attention to the elevator when I worked nights. She described how each night around three a.m., the elevator travelled to each floor of the hospital and the doors opened automatically and how the ghost of an elderly

nun, who was a nurse, would get off and walk the corridors. The nun visited the dying to comfort them and after she left, the patient died. Whatever was happening to these patients, I started believing in the existence of unexplainable experiences as playing an important and unique role in my profession.

The mystical stories I heard from other nurses about their dying patients came back to me as I laid beside my dad. I knew that Dad would die very soon and that his condition would now deteriorate quickly. I knew this because I believe I witnessed the leaving of my father's spirit "when medicine's superficial control" (Frank, 1995, p. 126) of Dad's health yielded to a higher power. I had a powerful and peaceful "sense that my father's soul had transcended the somatic entrapment that bound him for so long" (Frank, 1995, p. 151). Three years after my father's death, it is the exquisite memory of this experience that sustains me in my grief.

Within two hours of my mysterious experience in Dad's room, his condition deteriorated. The rhythm of his breathing changed. There was a liquid sound when he exhaled and inhaled. Fluid collected at the back of his throat and in his upper chest. The sound terrified me. I knew what this meant and I knew what was happening. Fluid was accumulating in Dad's lungs. *This is how he feared dying. This is what he dreaded most.*

I pressed the nurse's call button and within minutes two nurses responded. We discussed the change in Dad's condition. I informed them about my father's years of anxiety worrying about dying this way. I suggested they suction Dad to keep him comfortable. Remembering that Dad choked easily, I requested he receive morphine before they began

suctioning. The morphine would regulate Dad's breathing, ease his gasping, help him to tolerate the procedure and keep him comfortable.

In my career I suctioned many patients, which involves inserting the tip of a narrow tube that is connected to a pump. This tube vacuums excess liquid or phlegm from the mouth and/or throat. Suctioning is not a pleasant procedure for either nurse or patient but the beneficial effects can be immediate. The patient's breathing improves, he or she relaxes, and is comfortable again.

Even though it was 2:00 a.m., Dad's doctor came in the room. He checked Dad's pulse and listened to his chest with his stethoscope. I repeated what I said to the nurses about suctioning Dad and about the morphine. Again I explained how Dad was terrified of dying in congestive failure. He listened and asked "*If I wanted someone else in my family to come in and sit with me?*" I explained "*No.*" *That my family had done everything before I arrived and they needed rest. It was now my turn to look after Dad, that this was my way of looking after the rest of my family.* I thanked him for coming in the middle of the night. He smiled and checked Dad again before leaving.

When the nurse placed the suction tube at the back of Dad's throat where a normal response would be expected (i.e., a gag reflex), there was none. The absence of this reflex reaction during suctioning indicated the probability that Dad suffered another stroke and the level of this unconsciousness deepened.

As Dad's daughter my singular thought was to keep him comfortable, to protect his dignity and to help him die without pain or anxiety. As a nurse I was confident that my father was comfortable and from my experience with dying patients I knew it was possible for Dad

to die the way he wanted. I knew that as his condition deteriorated, the symptoms associated with his dying would change and that my watchful attention to identify these symptoms and to take appropriate care to maintain comfort until Dad died was now my duty. Dying is not a static process. Because of the complex issues involved in dying and death, families may be required to make medical decisions such as morphine dosages and frequencies until the time when death occurs.

Decision making for grieving family members is exhausting and health care professionals must be alert and observant to the needs of the family throughout the dying and death process. To lessen the impact of such experiences, nurses need to establish collaborative relationships with grieving families and become the family's guide through this life changing experience.

In palliative care I watched as nurses maintained close, supportive contact with grieving individuals and families. I listened to my colleagues as they answered questions, and explained medication and equipment use in a clear and concise, yet compassionate manner. An atmosphere of mutual respect and honesty is necessary and families should feel comfortable questioning the types of treatment and procedures. This sharing of information decreases anxiety in grieving family members and can assist them in making the experience of their loved one's death less overwhelming.

Dad's nurse medicated him and suctioned the fluid from his mouth and throat. With the fluid removed, Dad's breathing improved and he stopped gasping for air, but his general condition continued to deteriorate.

I requested morphine for Dad because it is a narcotic/analgesic (pain reliever) useful in palliative care. The medication slows the patient's breathing, making respirations easier, more effective and calms the patient. Family members of dying patients are concerned about their loved one receiving morphine. They worry the drug will cause addiction or will hasten death. As a nurse I have no such concerns. From my experience with dying patients it is important to remember what is most beneficial to the patient, and now my dad's comfort was crucial. Family members must remember that it is not the number of days of life that are important, but the quality of life during those days. End-of-life treatment decisions should be guided by the "best interest principle" (Buchanan & Brock, 1992, p. 123), focusing on the present and future interests of the incompetent patient.

As a nurse, the principle of doing what is best for my patients guides my nursing care. In practice the principle is uncomplicated. In geriatric and palliative care these guidelines provide welcome clarity when difficult dying and death decisions are required. Supported by these principles, I can speak with grieving family members and guide them through the emotional issues related to palliative care.

Utilizing this framework to look after my father's palliative care helped me to understand the less discussed issues associated with decision making I had not explored.

Since Dad's heart attack in 1991, the phrase what would be best for him was part of my father's lived experience. When the stroke left him unconscious and unable to express what medical treatment he would consider to be in his best interest, my mother, brothers, sisters and I made the decision we thought he would make. Although our decision making was guided by our knowledge of Dad's own wishes, the hurtful realization was that he would



die when we chose the treatment that was in his best interest. In order to honour our father's final wishes, our family focused on *his* needs to die with dignity, rather than *our* need to hold on to him.

After witnessing my family's experience with Dad, I now appreciate the emotional weight of making the DNR decision. I now consider such a choice an act of great selflessness and self sacrifice whereby the dying patient's death with dignity surpasses the grief needs of the living.

Personal Reflections - December 19, 1996: Morning of the Third Day

Dad looked exhausted. Last night drained much of his already depleted energy. He looked weaker this morning than he did yesterday. He looked thinner, and smaller as if he was melting away in front of me. Since the episode in the middle of the night, Dad seemed to be at a deeper level of unconsciousness. I was with him long enough to notice how different levels of consciousness were associated with changes in the rhythm of his breathing.

Throughout the day the nursing staff came in the room to change Dad's position and maintain a watchful eye on his weakening condition. While caring for Dad, they inquired how I was feeling and asked about my family. We discussed the changes in Dad's condition and agreed he was weaker. The nurses informed me there was a reddened pressure area on Dad's left hip that they were watching. Dad's circulation was poor and he was thin. There was no fat or muscle padding to cover his bones. The nurses changed Dad's position and rolled him onto a sheepskin thus hoping to prevent further pressure.

I left the room while the nurses were with Dad. I called home and spoke with Mom and told her how Dad was feeling. When I returned, a strong odor dominated the room. The

stench smelled like feces, and I thought Dad had had a bowel movement. I felt my dad's humiliation and vulnerability as the "impure cloud" (Howes, 1991, p. 138) engulfed Dad and betrayed his dignity. The smell's shapelessness escaping from Dad's body connected with my image of my father's frailty, but the combination seemed out of place in the midst of the room's environment of compassion, love, and peace.

Having been in Dad's room for over eight hours without leaving, my sense of smell was accustomed to all of the odors within. Returning to the room, I was surprised by the intensity of the dominant smell. Together with Dad's nurses we tried finding the cause of the odor.

Unpleasant odors are common in health care environments. Physicians and nurses work in an atmosphere immersed in smells. Odors from exotic medicinal liquids, lotions and sprays, monotonous scents from cleaning solutions, the stench of urine, human excrement, and diseased bodies intermingle and endure continuously.

Nurses learn to use their sense of smell as an observational skill when providing patient care. Early in my nursing education, I learned to appreciate the significance of odors associated with the process of disease or the level of wellness within patients. Assessing patients, involved noting the presence or absence of anticipated or unusual smells and these odors were perceived as beneficial or detrimental to the patient. Nurses must create and maintain a comfortable environment for patients and their family members by preventing, controlling or disguising unpleasant or offensive smells.

Repugnant odors are a constant concern in providing quality patient care. When a patient is dying, it is crucial to try to ensure an odor free environment for the patient and their grieving loved ones. Recollections of the family's grieving process should not be distracted or overwhelmed by memories of the stench filled environment of their loved one's dying, although the olfactory nerves are the most primitive and the closest sensory association to memory.

As a professional I understand the biological changes that occur during the dying and death process. From my experience with grieving families in geriatrics and palliative care, I realize each individual attempts to understand dying and death in a unique manner and that "everyone wants to know the details of dying though few are willing to say so" (Nuland, 1995, p. xv). Most families who witness the deteriorating condition of their dying loved-one and achieve some level of awareness regarding the physical changes they anticipate occurring to the patient's appearance. Not all changes associated with the dying process can be anticipated and when unexpected events happen, the grief experience of survivors is affected in a negative manner. Offensive odors associated with the dying and death process do not always occur and can be difficult to anticipate, but when they do occur, problems are inevitable. Disturbing odors affect the family's ability to remain at the bedside of their dying loved-one and thus influence the continuation of their deathbed vigil. The experience of visiting their dying loved-one becomes unpleasant and too unbearable for them to continue.

During my nursing shifts, I often spoke with grieving families about the type of dying and death experience they could anticipate with their loved one. In situations where the dying patient had open wounds or specific disease processes such as cancer, I spoke with the next-

of-kin about the potential cause of any anticipated smells and explained what nursing care procedures would help to lessen the impact of the odor, thus making the time spent with their dying family member more tolerable. My dying father had neither open wounds or cancer so I did not anticipate unpleasant odors as part of my own grief experience.

My personal understanding of Dad's dying experience was wrong and my mother, brothers, sisters and I all encountered a stench in Dad's hospital room. This made visitations troublesome for my mother and contributed to her inability to visit with Dad during the final two days of his life.

Following the evening of December 18, when most of my immediate family sat around our dying father's hospital bed, my mother, brother Murray, and my youngest sister Lisa chose to remain at home and remember Dad as he was prior to his stroke. Seeing Dad so incapacitated by the stroke and dying was devastating for them.

The source of the unpleasant odor was a severe halitosis caused by Dad's dry mouth. Since his stroke on December 17, oral intake of food and fluid stopped and Dad received fluids by intravenous therapy. The resulting oral dehydration caused dryness in the mucous lining of my father's mouth. Physiological imbalances brought on by the oral dehydration produced significant increased ketone levels and acidosis which furthered the severity of the halitosis. Beyond the sensations of thirstiness or dryness, Dad appeared to be comfortable and not stressed by this minor condition.

Unconscious, unable to swallow, and close to dying, the most reasonable nursing intervention for Dad was to provide frequent, meticulous mouth care. I applied mouthwash to my father's mouth, teeth, and tongue to keep these surfaces moist and use the scent of the

liquid wash to lessen the halitosis. With the unpleasant odor less evident, the room environment was improved and so too was the dignity of my father's dying experience.

Shortly after 1:00 p.m. a staff member inquired whether or not I wanted Dad transferred to the hospital's Palliative Care Unit. The question jolted my thinking. I answered *no* and explained that the staff on the medical/surgical ward were taking good care of him and were already doing everything to keep him comfortable. I thanked the nurse for asking but said *we would be okay with Dad staying here.*

Although I was aware of our family's decision to reject aggressive medical treatment for Dad and our choice of death with comfort and dignity, I was stunned by her question. Hearing a stranger associate my father's name with the words "palliative care," emphasized the enormity of my new reality; Dad is dying. Her question forced me to think about palliative care and what those words mean to Dad, my mother, brothers and sisters.

Sitting alone with Dad, I looked around the small room and wondered if I was being selfish in deciding to keep Dad on this medical/surgical ward. Would he be better off where the rooms are decorated and furnished to create a home-like environment for the dying patient and their grieving family? Would a palliative care room, with its pastel coloured walls and printed curtains on the windows make a difference in the type of death Dad would experience? Could my father die with dignity and peace in this small, unadorned, colourless room?

Trying to move beyond my obsession with the nondescript environment of Dad's hospital room and I focused on what I knew about palliative care. That it represents a philosophy of care for those who are dying and is not dependent on location; it is not reliant

on this dingy, plain little room. Rather, it is dependent on the philosophy of care of the nursing staff and their desire, knowledge, and ability to support dying patients and their loved ones through the process of dying and death. Watching Dad's nurses I knew that their philosophy of care would support the type of dying and death care Dad needed.

Whenever the nurses provided care for Dad, I noticed how they touched him, how they repositioned his limp body with smooth, gentle movements of tenderness and respect. I listened as they called him by name and spoke to my father whenever they were in the room. As a nurse and a daughter, I was comfortable with the care Dad was receiving. I had no reason to consider transferring Dad, in my opinion the staff were providing the palliative care Dad required. Also, my mother, brothers and sisters were familiar with this little room and acquainted with the nursing staff. As much as continuity of care is important to my father's dying, it is as important to my family's grief. As Faifel (1977) suggests "the role of the nurse is to make the process of dying an experience in living" (p. 139) and the nurses who are caring for my father were doing this.

In the mid 1980s, I was a member of this hospital's palliative care original committee who considered establishing a specialized unit to address the unique needs of terminally ill patients and their families. Remembering this, I rested my head on Dad's shoulder. I hugged him and whispered, "*We'll be okay Dad. You'll be just fine right here.*"

Since Dad's death, a few people have asked me why my family chose to have him die in the hospital and not at home. These people know I am a nurse with a background in geriatrics and palliative care and assumed I would encourage my mother, brothers and sisters to have Dad live his final days in his own bedroom. They suggested that my special bond with

Dad as a daughter and a nurse and his close relationship with his family should have resulted in our father dying at home.

The issue of supporting Dad dying in his bedroom in the familiar surroundings of our home was never a consideration. Although this type of dying at home was not discussed by Dad before his stroke, my family never raised it as an option after the stroke occurred. Without ever having talked about the benefits and drawbacks of this type of palliative care with him, I knew that having Dad die at home was not an acceptable option.

Following Dad's death, grieving family members shared their stories of caring for dying loved ones in their homes. Their stories revealed a unique emotional insight into the dying at home experience. Years after the death, unsettling memories of their loved one's dying continues to impact their lives in a manner seldom mentioned in home care literature.

One middle aged woman explained how she had to sell the bed on which her mother died. She could never consider sleeping in the bed and that it was too difficult for her to even see. A middle age couple's grief story was more dramatic. Selling the bed where their family member died provided very little grief support. Redecorating the room with fresh paint and new furniture also failed to help. Following years of feeling uncomfortable in their own home, they sold the house. This couple shared how he and his wife would never again consider being involved in caring for a dying loved one in their home. Their lives were affected by the death in a manner that neither of them remembers the experience in a meaningful way that supports their grieving.

Professionally, I recognize the increasing interest and practice of terminally ill patients dying at home and that for some families "home-based care is one of the most growing

segments of the health care delivery system” (Van Ort & Woodtli, 1989, p. 5). In this changing societal milieu, however, a new extreme is now occurring where home care is the *only* option being promoted and choice is limited. Without providing choice for terminally ill patients and their grieving families, the survivor’s grief experience is affected in a significant way. For our family, a hospital death for our dad was the proper choice to make for him and for us.

As a daughter, I understand how the experience of a home death could be comforting for dying patients, including my father. My concern with Dad dying at home focused on the needs of his survivors-my mother. I knew that she would not be able to live alone in the house if Dad died there, and I also knew she would never again sleep in the same room. As much as I wanted to care for the needs of my *dying* father, I also wanted to care for the grieving needs of my mother’s *living*.

Personal Reflections - December 19, 1996 : Late Afternoon - Crossing Boundaries

Dad’s temperature was high. In the past I witnessed other stroke patients with fevers. I spoke with the nurses and I told them I would give Dad an alcohol sponge bath, to help bring down his temperature and make him more comfortable. The nurses thanked me for my help and provided me with a very large aluminum bowl filled with ice, a large electrical fan to blow across the ice to produce cool air around Dad, and alcohol to mix with cool bath water. This simple treatment helped my patients in the past, and I hoped it would work again.

For many stroke victims, internal temperature control is difficult. When brain injury from the stroke involves the hypothalamus a variety of symptoms may result (Chaffee & Greiheimer, 1964) which include: 1) diabetes insipidus, the condition in which a patient



passes excessive amounts of dilute, sugar free urine, 2) obesity; 3) pathologic sleep during which the patient sleeps abnormally long periods of time; and, 4) loss of temperature control. From what I could see, Dad exhibited at least these last two symptoms.

As I did so many times in the past for other patients, I exposed Dad's motionless body one area at a time and washed the surface of his skin with the cool liquid. Talking to Dad's sleeping face I explained what I was doing throughout the bath. *"I know you don't like a draft Dad, but I have to do this to get your temperature down. You're burning up."*

Being a registered nurse, I am a member of a health care profession where the unclothed body is touched by many pairs of hands (Fox, 1989) and worked upon and handled in many ways. The touching of a body's cavities, orifices and private regions that are touched in the most private and intimate relationships are common occurrences within a medical setting. A reciprocation of touch between care providers and care recipients is part of what nurses do. Nurses and patients are in close physical contact during the exchange of giving and receiving care. Within the hospital environment unfamiliarity and physical closeness exist side-by-side where strangers care for the bodies of other strangers. Relationships are established with a limited knowledge of each other, over a restricted period of time to achieve a specific outcome and boundaries define "who participates and how" (Minuchin, cited in Wright & Leahey, 1984, p. 27).

This exchange of physical closeness which includes bathing made me feel awkward. The cleansing of a stranger's body is a humbling experience that reminds me of the human frailties which interconnects us all, and how interdependent we are.

In September 1968, I bathed my first patient, a 48-year-old man who suffered a heart attack. As a new nurse I was embarrassed as he was by the procedure, but it was his voice that broke the uncomfortable tension between us. The comment he made never lost its significance for me. Looking at my father's incapacitated dying body my patient's words "*once a man, twice a child*" came back to me in a heartbreaking, unfamiliar fashion.

When I informed the nurses I would give Dad a bath, I did not anticipate feeling anything beyond the familiar awkwardness I experienced with other patients. I wanted to help Dad feel comfortable. I had the knowledge to do what was necessary and I volunteered. Dad's nurses were confident in my abilities and they could entrust me with Dad's well-being. I felt uncomfortable for Dad while bathing him: I knew how shy he is about his body. I never saw Dad naked. In my mind I imagined what he would be saying from sheer embarrassment, "*you don't need to do all this, Sanie. Daddy will be okay.*"

Before the bath, the extent of my involvement with Dad's care was as his advocate. My nurse's knowledge and experience in geriatrics made it possible for me to recommend and support his medical decisions and treatment. Aside from giving Dad an injection for discomfort caused by a kidney stone fifteen years ago, my participation has not been as a *hands-on* care giver, until now.

The ambiguity between my role as a nurse and Dad's daughter was uncomfortable. Bathing my father's body and seeing his nakedness, I felt like an intruder, a voyeur peeking at my own father and breaching some moral law. I felt restricted by invisible but real boundaries between Dad and me. Familiar nursing movements and gestures were clumsy and I talked

incessantly. I struggled to make sense of what was happening to me; I wanted to do this for Dad. I wanted to make him comfortable.

I removed Dad's perspiration dampened johnny shirt and working from under the sheet, passed the wet face cloth across Dad's abdomen and right side. Moving the washcloth back and forth against his skin, I noticed the telltale surgical scars recording the years of Dad's health problems. The pale coloured cut marks reminded me of all of those times I feared for Dad's life and prayed I would not lose him.

Putting the face cloth down I touched the scars with my finger tips and spoke in a whisper, *"I remember this scar. This was when your appendix ruptured. My heavens Dad, I was in grade 12! I remember the doctors kept arguing with you that it was from stress but you knew they were wrong. They even had a psychiatrist in to see you and you told him to get the hell out of your room after he called you crazy."*

Dad's body was skeleton thin under my touch. My father was never a big man, but illness now revealed his bones and he looked frail. As my hands moved across Dad's chest, I felt the rough, raised ridge of the scar from his open heart surgery. Dad often opened the first few buttons of his dress shirt to show the top of this scar, much like he would a medal of honour, but I had never seen the entire tracing of the surgeon's scalpel. I touched its surface and my insight as a nurse filled my head with graphic images of that day when Dad's chest laid wide open with him, helpless on an operating table and me, too far away to be with him. Stories of Dad's past illness filled my thoughts and as Frank (1995) explains "the ill body is not mute — it speaks in pains and symptoms but it is inarticulate" (p. 2). I finished Dad's sponge bath, and his body felt cooler, but he looked exhausted from the effects of the high

temperature. Loosening the sheet around his shoulders and I tilted the fan away from him. I hoped that he was comfortable. I kissed him on the cheek *“There Dad, that wasn’t that bad, was it? I hope you feel better.”*

For nurses in geriatrics and palliative care, witnessing a family member provide physical hands on care to their dying loved one is not uncommon. Relatives and close family friends often participate with care in whatever manner they can, from simple foot massages to more complex procedures such as tube feeding. I encouraged this level of physical care involvement whenever family members voiced an interest in doing so. However, I perceived their participation from a very limited perspective and failed to understand the complex nature of this involvement as part of anticipatory grief.

As a nurse the simple act of bathing my father taught me something important. I now realize that health care professionals must give more attention to the increased stress levels that result when there is physical care contact between a grieving family member and their dying loved one. According to Rolland (1994), the family member/sibling who performs the duties of the care-giver is at the greatest risk for emotional strain. As the severity of the illness escalates and the hope of improvement dwindles, care-givers involved in the physical care of a close family member feel a unique sense of anticipatory grief and loss.

Although family care givers are important in today’s restructured health care delivery system, their needs are underestimated and neglected. Without attending to the complex needs of the family care giver beyond that of physical stress, these familial care providers are at increased risk for complications in their grieving process.

Not long ago a fifty year old male social worker spoke with me about the changes occurring in long term health care. His eighty-six year old mother has required twenty-four hour nursing care for five years. He is an only child. His father is deceased and he and his mother have a close relationship. One afternoon a staff member from the nursing home called him to inquire what type of physical care he would provide for his mother. He was shocked at their suggestion.

He decided he could feed his mother and fix her hair. He stressed the other care as being too physical and too intimate. If he bathed his mother he said he would be as humiliated as she would be. He now feels guilt, that he said no to the nurses but added that he is still unable to consider this type of physical intimacy as part of his elderly mother's care. Although the initial question still shocks him and he feels he has let his mother down. Now that his mother can no longer speak, his grieving process as a son has intensified because of the inability to discuss his concerns.

In an article Mid-Life Panic (Underwood & DeMont, 1991) the author states an estimated 200,000 Canadians, are caught in the middle and suffer from the burden of caring for elderly parents, as well as their children. Dubbed the "sandwich generation" adult children are caught between the demands of two generations. Although some males do participate in care-giving, elder care is distinguished by having women perform eighty percent of the primary care. "Men can care about those things, too, but more than often they are not getting their hands dirty" (Faulder, 1995, p. 10). Men are more likely to be responsible for providing financial support whereas women provide the hands-on-care.

Recent changes in health care delivery tend to consider males and females to have an equal interest in and capable of participating as a familial caregiver to dying loved-ones. Prior to my personal experience, I was one of those health care professionals who witnessed sons and daughters at the bedside of their dying parent. As I observed what they were doing, I failed to consider what they were thinking or feeling. I accepted their experience of doing-for as a simple, but wonderful act of love and caring for someone they cherished. I now understand the experience of providing personal care to a dying loved one as being a very complex involvement that extends beyond gender and is influenced by the significance of intrapersonal boundaries that exist between individuals regardless of whether they are male or female.

Physicians and nurses must also realize that different cultures perceive a dying person in unique ways depending on their belief systems. There is a tremendous diversity among individual families and specific cultures regarding the experience of dying and death. Members of the medical care team need to be well-informed of a wide range of responses deemed *normal* and *acceptable* for families who are grieving rather than create assumptions based on their *own* professional or cultural practices and beliefs regarding the physical care of a dying loved-one.

The grief experience of bathing my dying father influences how I speak with grieving families about their involvement in providing hands-on physical care to their dying loved-one. As a nurse I encourage family members to tell health care professionals their feelings associated with being a care provider and to be honest about their reluctance or inability to be involved in bathing, dressing, or toileting a loved-one and not feel guilty or inadequate.

From my perspective as a nurse I no longer make assumptions about familial participation in providing hands-on care to dying family members. I accept more responsibility as a nurse to ask appropriate questions about how husbands, wives, sons, daughters, brothers and sisters feel about their role in assisting with patient care. As a daughter, the experience of bathing Dad was an unanticipated learning opportunity. Although the initial experience was uncomfortable, the memory of that intimacy I shared with my father remains vivid. As a nurse and a daughter, I learned the importance of how such caregiving experiences become significant grief memories that become recollections of a loved one's dying and death. According to the family member's comfort level and acceptance of their caregiver role, the reminiscences of unanticipated aspects of the dying experience can comfort grief survivors, or, contribute to the negative influences that complicate the grieving process.

Grief related to the caregiving is an important issue. The increasing participation of family members in caregiving requires further investigation and open, honest discussion about the long-lasting influences of this degree of end-of-life care involvement. As the health care delivery system strives to address the needs of dying patients and families, the needs of the patient are often viewed as more important than the needs of surviving grieving family members. Too frequent family members are involved in providing hands-on care without understanding the impact the experience will have on their lives. Families are left unprepared to deal with the emotional and physical demands they experience and their grieving process becomes overwhelming.

Care of dying patients must include comprehensive family care. Health care providers need to be sensitive to the individual grief needs of both the dying patient and all grieving family members. Physicians and nurses need to understand the total grief experience and how the decisions made regarding the family member's caregiver role, regardless of gender, influence the grief process which endures for years.

Personal Reflections - December 19, 1996: Evening - The Final Night

Tonight Donald, Jane and Jennifer, Jane's nineteen year old daughter visited. Their tiredness is the result of prolonged anxiety, fatigue, and the persistent visible reminder of Dad's failing health. This evening is more quiet than previous visits. My brother, sister and niece talked less with Dad and with each other. More time is spent touching Dad's hands and remembering in silence the memories of the past and their lost dreams of a future without him.

There is also a different mood. The quieter atmosphere appeared to be my family's way of continuing to make sense of what we were feeling and seeing as Dad's condition worsened. Every moment seemed longer than the one before. Time had greater significance. Being close to Dad, being able to reach over and touch him and feel his presence is most important. While Dad moved toward the end of his life, time together with him is more cherished and intense.

Each time my family visited I shared with them the events of the day. I informed my brother, sister and niece about the small changes in Dad's condition and updated them on the events that occurred since their last visit. I told them about Dad's elevated temperature, and my giving him an alcohol sponge bath. I discussed the physiological effects of the stroke and



explained that Dad's brain has been damaged thereby leaving it unable to control the body's temperature control system.

By sharing such information, I hoped to provide my brother, sister and niece some facts to alleviate their anxieties, keep them well informed about Dad's deteriorating condition, and make them feel a part of his final days of living.

My brother and sister brought me information from the rest of our family. They reminded me that my mother, brother Murray and sister Lisa would not be returning and how they were more comfortable remaining at home instead of visiting Dad in the hospital. They wanted me to know that they were thinking about Dad and me, and that they send their love to both of us.

Donald, Jane, and I understood the decision that the others made and we supported their decision to stay home. We were grateful knowing that Mom would not be alone during an intense time of anticipatory grief, participating in a different manner in the vigil we all shared.

For caregivers, death bed vigils are isolating. When the care provider is a family member he/she is often separated from their spouse, children and own siblings who are his/her support system during a crisis. When end-of-life vigils require the caregiver to stay at the bedside in a hospital, nursing home or palliative care unit, away from their familiar environment, regular routine and immediate family members, the risk of feeling isolated from other loved-ones increases. When this occurs, a caregiver requires special consideration to lessen their negative emotional situation.

Recognizing the possibility of *caregiver isolation* is crucial for health care professionals and for families with ill members. Sensitive support for the one who waits for death along with the ill family member is very important. Whether my family were aware they were supporting me during the time I spent with Dad, their regular visits, ongoing phone calls and the relaying of daily information of family happenings from home lessened the weight of my vigil. Knowing that my mother, brothers and sisters were close by comforted me and I looked forward to their visits.

Family death bed vigils are more evident at the bedside of a dying loved-one, when death occurs such as from an accident or a an aggressive illness. But in palliative care, death bed vigils are commonly a solitary experience for one grieving family member.

Participation by family members at a bedside vigil is never static because the individuals involved and the numbers of those participating often changes. As time passes and the duration of the vigil extends beyond days and months, those involved diminishes. Grieving family members return to their homes, continue on with the routine of their personal and professional lives, and wait from a distance for death to occur. For those who remain, the vigil creates a different grief memory.

Death bed vigils occur on hospital units with elder and palliative care, and patients dying alone without any type of support from family or friends is an infrequent occurrence. When a patient *is* alone and has no one to provide company, either by choice or circumstances, nursing staff and palliative care volunteers comfort and support patients though their dying and death process. Comprehensive palliative care addresses either

situation and strives to provide personalized end-of-life care for dying patients and their grieving loved ones.

Nurses are often challenged by their own commitment and desire to provide individualized quality palliative care to *all* dying patients and their families. Nurses strive to discover the needs of terminally ill patients and their loved-ones to better support and comfort them through the dying and death process. Through purposeful, sensitive inquiry and experienced observation, palliative care nursing staff assess and evaluate *continually* the ongoing needs of grieving patients and family members.

Guided by the fundamentals of the palliative care philosophy, comprehensive patient and family end-of-life care nurses adjust care strategies to meet the complex changes that occur as the patient's condition deteriorates and death occurs. From initial contact with the dying patient and their families, a multi-disciplinary palliative care team focus on anticipating and addressing the individualized grief needs of everyone affected by the death. Skilled, empathetic staff must emphasize the importance of meeting the unique grief needs identified by dying patients and their family members.

Around midnight when Jane and Jennifer left to go home, Donald seemed concerned over Dad's elevated, difficult to control temperature. I explained to my brother once again that I suspected the stroke damaged the part of Dad's brain that controls the body's temperature levels. Donald seemed dissatisfied with my explanation so when a male nurse came in to check on Dad, I asked him to speak with Donald.

Later on in the night during a less hectic period in his schedule, the same registered nurse returned to Dad's room and sat with Donald for thirty minutes, explaining the physical changes that occurred in Dad's brain due to his stroke. In his quiet explanation, the nurse reinforced what I told Donald earlier. My brother began to better understand the implications of our father's stroke and how the damage influenced the symptoms we were witnessing.

When situations occur such as the one that happened with Donald, nurses who are also family members must step back and permit another health professional to be involved. Nurses without a familial association to the individual provide a sense of objective authority to an explanation or problem solving issue that reinforces an inquiring family member's ability to accept the reasonableness of new information and apply it to a particular situation. Although I am a nurse, I realize that I am not always the best source of medical information for my loved ones. As much as I know that I am a nurse with specific knowledge and experiences, to my family I am a daughter, and a sister. This is no reflection upon my nurse's ability to be a capable, intelligent health professional, but within the context of my family I am first and foremost, a family member.

After the nurse left, Donald seemed distracted and whispered "*How much longer do you think Dad has?*" By the emotional hesitance in my brother's voice he needed to ask the question, but seemed reluctant to hear the answer. Taking a moment to respond, I replied as honestly as possible that *I could not give him an exact time, but according to my nursing experience caring for dying patients like Dad, he would not survive much longer. I was surprised that he lived through today.*

Donald seemed touched by my answer and reached for Dad's hand and whispered "*I love you Dad. God, I'm going to miss you.*"

Sitting in silence I watched as my youngest brother caressed Dad's hand and created another memory of these final days. Such an intense tenderness existed between my father and brother. I was witnessing the depths of their relationship that evolved over the forty-one years of my brother's life.

In palliative care environments, it's silence that often communicates. Silence signifies intense levels of interpersonal sharing and human connectiveness and it is in the absence of words that the richness of touch and eye contact enhances the relationship between dying patients and their grieving loved ones. Sitting or standing in silence is a ritualistic behavior that emphasizes the characteristic somberness associated with dying and grief. Health care professionals and family members tend to place more value on verbal communication and the family member's ability to talk freely about events and feelings surrounding the dying and death experience. This perspective places less value on silence and denies the power of this form of silent communication.

Nurses must realize and value the individual differences of communication and learn to appreciate that silence does not always indicate unspoken problems. Silence, although not well understood or tolerated by Western cultural behaviors, can signify a level of familiarity between individuals resulting in an increased ability to not speak and "that silence does not exist but is actively created by participants" (Bonvillain, 1993, p. 47).

Watching the interaction between my grieving brother and our dying father required no explanation. Their silence surrounded their closeness and it was all that was necessary to emphasize the depth of love present within their father/son relationship and the poignancy of this time together.

Silence or words — either communication is an essential and effective communication and is critical in a medical setting. Nurses and physicians must be skilled, well-informed communicators who understand the different functions and methods of expressing information, thought, and emotion. From the beginning days of my nursing education the importance of the give-and-take of communicative interactions (Bonvillain, 1993, p. 1) between nurses, patients and their families was stressed. Thirty-one years after my initial introduction to human communication, the patterns of verbal and nonverbal language continue to interest me.

Grieving family members often sit at the bedside of a dying relative without speaking. Silenced by complex feelings of awkwardness, anxiety, guilt and fear, some families sit mutely for hours.

Watching these families while on duty, I perceived their silence to be the absence of communication. Knocking on the door upon entering and I spoke with them. I used conversation to interrupt their silence which made me uncomfortable. Without an understanding of the importance of silence in the grief process, I did not appreciate the intimacy of interpersonal interaction that the absence of words foster. Witnessing my father's final days of life influenced my knowledge of silence and my response to this form of

communication. This experience altered the way I support grieving families and how I teach palliative care volunteers.

Following Dad's death, I no longer feel uncomfortable with silence and have no desire to interrupt the quiet of a dying patient's room. Instead, I attempt to understand how individual family members communicate with each other and try to support the communicative style they need to endure their feelings of grief and loss.

My dad's dying did not end the father/daughter relationship we shared. In the final days of his life, the closeness continued between us. Sitting and talking with my unconscious father I looked at his handsome face and gentle hands. Trying to force these images into the depths of my memory, I hoped to find a place where the recollection of every detail of him would remain safe and unaffected by the passage of time. The hours I spent alone with my dying father are grief memories that comfort me in his absence.

As Dad's condition weakened, I sat in comfortable silence tracing every detail of his face with my eyes. I was hyper-vigilant about remembering our final days together. I needed these impressions of my father to last the rest of my lifetime. I surrounded my father and myself in auditory and visual silence separating us from external distractions that interfered with my need to emblazon precise details. Reading a magazine repulsed me. I needed to fill my eyes with only Dad.

During my years in long term and palliative care I witnessed grieving family members sitting in their silent, late night bedside vigils in dim lit rooms. Sympathetic toward their grief, I encouraged them to lie down and rest or go home and sleep. My suggestions were made

with the best intentions and genuine concern for the well-being of the grieving family members; I thought I understood their needs, their grieving. However, I did not recognize my limited knowledge until I experienced the death bed vigil for my own father.

I now understand the overwhelming need of family members to stay at the bedside of a dying loved-one. This need extends beyond self-interest and comfort. I understand the extraordinary urge to place the vigil as the center of existence and focus on nothing else. I also understand the unequivocal sense of clarity that grief creates that leaves no option. What is necessary is to remain at the bedside and wait, without hesitation or thought of how long the vigil lasts, being there, being present at the time of death is the acceptable thing to do.

During the four days spent sitting with Dad, well meaning, well intentioned acquaintances suggested I leave the hospital and go home and rest. These people worried about me becoming exhausted and risking the chance of my becoming ill. From an outsider's perspective, the stress associated with the long vigil hours are harmful both physically and emotionally. Their understanding of the dying experience focused on my physical exhaustion and failed to recognize my spiritual and emotional need to stay with Dad.

Similar to my previous understanding of the vigil experience of others as being exhausting, staying with my dying father was not considered by some to be beneficial in supporting my sense of loss. My mother, brothers and sisters knew how important it was for me to remain with Dad. My family understood my compelling desire to stay with our father until he died. They never questioned my need to stay. They knew it was far less stressful for me to remain in the hospital with Dad than it would be for me to leave him.



Dad's face was pale from exhaustion. Etched on his perspiring skin was the stress of the past hours of prolonged physical exertion. Dad's body gave all it had in fighting his elevated temperature. Losing fluid from sweating his body looked smaller than before. Slowly and steadily his body's resources were being depleting. As a nurse I knew my father could not tolerate this strain much longer and that death was hours away. I struggled to stay awake. Sleep would separate me from Dad. I wanted to be with him and alert when he died.

That night was not the first time I felt compelled to watch over Dad. In July 1991, when he returned home from the hospital after suffering his heart attack, I stayed in Dad's bedroom with him. There were two single beds bordering either side of the room and I slept in one of them. Although feeling awkward with me being there he said nothing. He understood my need to stay.

Within seconds of remembering that time, multiple images from the past flashed, suspending me in time with my thoughts and emotions. I was frightened to leave Dad alone. I needed to hear him breath while he slept. I wanted to be there if he called out in the darkness with fear or discomfort. My own bedroom just next to Dad's was too far away. I was like a first-time mother watching her newborn sleep.

I smiled, remembering that after two nights with me sleeping in his room, Dad, explaining he would be okay, suggested I should sleep in my own room. "*Sanie, you're too old to be sleeping with your Daddy. I'll be alright. Don't you worry now dear, you need your sleep too . . . . Then he winked at me and teased — and anyway, your mother's getting jealous.*"

I agreed to sleep in my own bedroom but emphasized to Dad what I was feeling. I pleaded with him *“Okay Dad, but leave your bedroom door open just in case you need something during the night.”* Dad grinned and nodded, *“Well if I do Sanie, I’ll know where to find you-okay?”*

That memory seemed so real. When Dad experienced his heart attack, I thought he looked unwell and frail; six years later his general appearance was altered and he was wasting away. As Dad slept, his stillness was a rehearsal for his eternal sleep that lay ahead.

The night before Dad died, I laid beside him and rested my hand over his heart. Unlike six years ago, when I pleaded with Dad to fight to stay alive and prayed for him to live, I now begged his heart to just stop and let him die. Where I once thought of death as being a dark predator, I now saw my father’s dying as an offering of light, comfort and peace. Despite such a prayer, I did not reach the level of acceptance of my father’s death as the final stage of grief (Kübler Ross, 1969). My thinking was a continuation of realizing that living was no longer possible for Dad and that a poor quality of life was in fact unacceptable. In the past, when I told Dad to fight to live, I fought along with him. Now, we *welcomed* death together. I was ready to let Dad go; the time for fighting for his life had passed.

It was well past midnight. Donald was exhausted and fell asleep with his head resting on the bedrail of Dad’s bed. I touched his shoulder and suggested he go home. Still groggy from fatigue, he whispered *he was afraid to leave and wanted to be with Dad when he died.* Squinting through bloodshot eyes he said he has never felt so tired and asked *“Do you think Dad will make it through the night?”* I answered *it was hard to tell. If he had a quiet night*

*with no other problems he should be okay.* I promised Donald if he went home I would call during the night if Dad's condition deteriorated further. Feeling more comfortable about leaving, Donald decided to go home and return in the morning. Before leaving, he kissed Dad on the forehead and told him he loved him, gave me a hug goodnight, and disappeared quietly into the semi darkness of the empty hospital corridor.

Without Donald around I was aware of my own fatigue. It was difficult for me to concentrate, I was nauseated and dizzy. The last time I slept was five days ago before receiving the call that Dad had his stroke. Pulling my chair closer to Dad's bed, I sat down and rested my head on the pillow trying to rest.

A little while later, two nurses came in to check on Dad and to change his position. They reminded me that there was a small fold-out cot in the corner of Dad's room and suggested I would be more comfortable resting there. One of them who had been on duty each night since I arrived, remarked that she never saw me sleeping and encouraged me to rest and take care of myself, that the day's ahead would be difficult.

Although admitting my fatigue I assured them that I would be fine. I did agree to sleep on the cot, if someone would wake me if there was any change in Dad's condition, regardless of how minor it might seem. Both nurses agreed and added that they would look in on Dad more often while I slept. After they left I unfolded the cot, pulled a blanket over my shoulders and fell into a deep sleep.

Small fold-away cots and Lazyboy recliner chairs are familiar furnishings in the patient rooms of palliative care units because the environments are designed to address the needs of

the dying patient and their grieving family members throughout the dying and death process. The cots and recliner chairs provide a way for grief weary visitors to find some physical respite while waiting at the bedside of a dying loved-one or friend.

Within a comprehensive palliative care philosophy, grieving family members are encouraged to experience the dying and death of their loved one in a manner that is meaningful for them. Family members have the option to stay through the night with their loved ones but the choice is theirs. Part of palliative care nursing requires skillful observation of the behaviors of family members and nurses must anticipate any physical, emotional or spiritual grief related concerns antagonized by a family member's heightened stress and fatigue.

Palliative and geriatric nursing is a unique patient/family care experience for health care professionals. Unlike other areas of patient care where clients remain for short periods of time, elderly and terminally ill patients stay longer and have more sustained contact with staff. This additional time gives nurses increased opportunity to familiarize themselves with the personalities and behaviors of patients and their families thus enhancing their ability to anticipate and identify stress-related problems.

During the eighteen years I worked in geriatric care, the average length of patient stay was just under six years; several other patients exceeded this time and one elderly lady was a patient of mine for twelve years. Starting from the time this lady was admitted up until she died, I was accustomed to her usual physical responses and behaviors and was able to differentiate between signs of her being stressed and being ill. I knew what frightened and caused her anxiety. As her nurse, I limited the possibility of these troublesome situations

occurring and protected her. Familiarity with this patient helped me provide individualized nursing care and support her quality of life.

Although I was with my dying father for a few days, my twenty-four hour presence in his room increased the opportunity for the nursing staff to know me. During their frequent visits to Dad's room, they observed my behavior and knew that I had not slept for a number of days. From experiences with other dying patients and their families, the nurses recognized the increased potential for me experiencing grief problems because of my being exhausted. By suggesting that I use the cot and sleep, the nurses were helping me make decisions regarding my health when I was too tired to think. When the two nurses informed me that they would watch over Dad while I slept, they gave me the security and comfort to relinquish my feelings of hyper-vigilance if only temporarily and sleep.

After sleeping for two hours I awoke, shocked that I slept so long. I got up from the cot and rushed to Dad's bedside to check if he was still alright. I was frightened he had died while I slept. I checked his pulse and watched and listened for him to breath. He was still alive. I whispered "*Thank you God*" and apologized to Dad for sleeping so long. I pulled my chair tight up against the bed and decided to stay awake this time. The fear of Dad dying while I slept filled me with a burst of adrenalin and I was wide awake once again.

#### Personal Reflections -December 20, 1996: The Final Day

Dad is closer to death on this morning. His breathing is shallow with blank periods between breaths when his breathing appeared to stop. Then, after a long period, begins again.

I recognized these respiratory changes as pre-death apnea caused by low levels of oxygen in Dad's brain.

My father's skin colour is becoming more pale and his hands and feet are cool to touch. Dad's circulation is slowing down and his body's natural survival mechanism is struggling to combat this final trauma. Dad's body could survive without arms and legs but not without the major organs located in his trunk and head. My dying father's circulating blood supply is flowing to the essential parts of his body attempting to keep him alive.

For the past few days, a urinary catheter drainage bag contained less and less amounts of dark coloured concentrated urine, signifying the slowing down of kidney function and the beginning indications of kidney failure. Based on my past nursing experiences, everything I noticed about my Dad's changing condition indicated that he could not survive the day.

At mid-morning two nurses came in Dad's room to bathe him and change his position. While the nurses were with Dad, I took the opportunity to walk down the corridor and call Mom and tell my family about the changes in Dad's condition. I tried keeping my mother informed so she would not be shocked when Dad died. Mom and I talked about how she was feeling and I returned to Dad's room.

As soon as I touched the outside of Dad's door and before walking inside, I met one of the nurses coming out to look for me. Her body movements were quick and her face filled with anxiety. As soon as our eyes met she whispered "*Thank God you are here! I was worried . . . .*" I interrupted her in mid-sentence "*Dad stopped breathing when you turned him over, didn't he?*" She nodded in agreement and added "*But he started again and he is okay right now. I am just glad you are here. I know how much you want to be with your Dad when he*

*dies.*” Following her into Dad’s room I thanked the two nurses for their kindness and consideration. When they left, I collapsed the bed’s side rail so I could sit on the chair with my head next to his. Holding his hand in mine I cried and told Dad that I loved him.

When patients are very close to death, changes in their body positioning can cause breathing to stop. Depending on the severity of circulatory impairment to the patient’s brain and heart, combined with the effects of the particular underlying illness or disease, breathing may or may not start again. This irregular intermittent respiratory rhythm of a dying patient’s breathing is a significant indication death is imminent. While other changes in my father’s condition would and could occur before he died, my family’s death bed vigil was coming to a close. The day arrived when Dad’s life would end.

Dying is a complex physiological phenomena “preceded by a series of irreversible biological events causing cumulative cellular destruction from which the individual cannot recover” (Durham & Weiss, 1977, p. 44). Although death depends on the disease involved, dying is different for each individual and includes numerous physiological *hallmark* changes that occur as the patient’s life nears to the end.

Although I was in the hospital with Dad to support my mother, brothers and sisters to this point, my years of nursing experience made me aware my father’s *death* will challenge my family in a different way. It was now that my care and attention is needed most. As Dad’s grieving daughter and a nurse, helping the rest of my family and myself survive this day is my greatest challenge.

I was sitting with my eyes closed and my head resting on Dad's shoulder when the door opened, and without explanation a stretcher was wheeled into the room and pushed against the side of my father's bed. This was something unexpected. I lifted my head in complete confusion and questioned what the stretcher was for. In a matter-of-fact manner I was informed "*The doctor ordered it.*" Still confused and now angry, I asked "*Why?*" and whispered "*What good is this going to do? He's dying.*" Seeing the tears in my eyes and hearing the hurt and frustration in my voice, the technician and I began talking. In an unsympathetic manner, the X-Ray technician explained "*The doctor wants to do a CAT scan on Mr. Hall. If you need to know more you have to talk with him.*"

I struggled to know what to do. The nurses just bathed Dad, he looked more peaceful and more comfortable than he had in days, and I questioned the need to disturb him when he was so close to death. I also respected Dad's doctor and I knew he would order this examination only if it was necessary. In the past, he used good judgement caring for my father and I had no reason to distrust his caring wisdom. Helping transfer Dad's limp, unresponsive body from his warm bed to the narrow metal framed stretcher, I felt uncomfortable disturbing his peacefulness and apologized for what I was doing. I kissed his cheek and whispered in his ear "*I am sorry I have to do this Dad; your doctor wants to take an x-ray of your head. It won't take very long and I'll stay with you.*" When we arrived at the X-Ray room, seeing Dad lying flat on his back just before the huge CAT scan moved into position around him, I was overwhelmed by his death like appearance and was grateful knowing that this procedure will not compromise Dad's dignity or make him uncomfortable.



“A CAT (computerized axial tomography) scanner takes a special type of x-ray of parts of the body such as the brain, that do not form clear images on conventional x-rays” (Kunz, 1982, p. 277). This procedure is capable of examining the location and severity of brain damage sustained from a stroke and provides physicians with precise information to guide medical care and treatment strategies.

When the X-Ray technician referred to the examination as a CAT scan, I understood what she meant, but without receiving further information about the procedure I wondered how often this lack of communication occurs and how other grieving families deal with this issue.

Like all disciplines, the medical vocabulary is intimidating to outsiders. Learning medical terminology was a difficult yet exciting experience for me. I remember novice nursing students revealing their limited expertise and knowledge by using new and unfamiliar esoteric terms and phrases at every available opportunity. The new language gave students a sense of superiority and separateness from others. In the presence of non-health care professionals nurses could speak in their nurses' voice and no one understood.

The working language of health care professionals is foreign to outsiders not involved in the medical care system. Complex sounding terminology, acronyms and medical jargon mingle as multi disciplined staff manipulate and maneuver patient's bodies in and out, under and through an inexhaustible maze of medical equipment and terminology. Patients and families unfamiliar with the ethos of the health care system experience unnecessary heightened levels of stress when health care professionals fail to recognize the differences that exist

between themselves and their clients. This interferes with the ability of both to comprehend the roles and participation of each other in the health care system they often share.

Within five minutes the CAT scan is completed. Dad is transferred onto the stretcher and wheeled back to his room appearing to have suffered no ill effects from the procedure. With the technician gone, I repositioned Dad in his bed hoping to make him as comfortable as before. I sat with my head resting on my father's pillow and again enjoyed being alone with him.

Mid-morning routine visitations from laboratory technicians interrupted the peaceful quiet in Dad's room. On two different occasions technicians from the hematology department came to take samples of Dad's blood and twice I explained that I wanted my father left alone, that blood tests would serve no purpose, and that I wanted my father's final hours of life to be peaceful. On both occasions the technicians listened and without any argument, left the room. I was grateful to be with my father and able to be his advocate. If I did not refuse those blood tests Dad would have to endure medical procedures that served no purpose.

Patients and family members are uninformed about their rights to refuse or accept medical treatment. Most patients accept health care professionals as authoritative decision makers and never consider challenging a physician's order or inquiring about available treatment options. Health care professionals further perpetuate this practice by not informing patients and family members of the rights and responsibilities they have regarding health care for themselves and their families. Functioning as my Dad's advocate was a natural progression for me because my basic nursing training encouraged nurses to be active patient care

advocates. We learned to encourage patients and family members to be involved in their own health and treatment decisions and be persistent, well-informed health care consumers capable of making decisions meaningful to their own concept of quality of life.

I was still wondering why Dad's doctor ordered the CAT scan now when my father was so close to death, when his physician came into the room. Anticipating my concern about the x-ray, he explained that he ordered the CAT scan to get a good look at Dad's brain and double check the amount of damage caused by the stroke and reassure himself that Dad was receiving appropriate treatment.

Speaking and taking time for me to understand helped prepare myself to accept what he was saying, the doctor explained "*The CAT scan shows Lorne suffered severe damage to his mid-brain and hope for any improvement is at best questionable.*" I heard Dad's physician suggest this type of damage before but each time I heard the explanation, the reality of what the stroke did to Dad's brain became more painful to bear. I listened as he continued to speak and reassured him our family's decision to support a DNR order continued to be the right decision. I reminded him of Dad's frequent comments about never wanting to live a life without a high quality of life and his fear of being physically and mentally impaired. As he was leaving, the doctor reminded me that he would keep Dad comfortable until the end and then asked if I was doing okay. The physician's empathy for my father and our family's needs was a constant support throughout our dying and death experience. His personal insight into our familiar grief was reflected in the sensitive care and attention he shared with each of us.

Dad's physician experienced the recent death of one of his own loved ones. His elderly mother who suffered a cardiac arrest was resuscitated and kept alive on a respirator. He

shared with me the deep sense of anguish he struggled with when faced with the decision of discontinuing her life support. He described this as the most difficult decision he and his family had ever made and that the painful memory of not permitting their mother to die without resuscitation haunts his family.

Hearing Dad's physician describe the findings of the CAT scan, I felt more comfortable about agreeing to the procedure. The test results supported the Do Not Resuscitate decision my mother, brothers and sisters made and I was comforted knowing we made the appropriate and right choice. It was important for me that my family avoid an anguished grief such as that experienced by Dad's physician and his loved ones.

Dad's pre-death symptoms are prominent. His breathing is indrawn and strained and he is beginning to gasp for air. When Donald, Jane and Jennifer came in the room Jane noticed the change in Dad's breathing and pleaded, "*Can't they give Dad something? I hate to see him breathing like that.*" I agreed and told her I just asked the nurses to give Dad some morphine. As Jane and I were talking, a nurse came in the room and gave Dad an injection of morphine. Soon our father is breathing much easier, and he seemed comfortable and looked peaceful. Satisfied that Dad is comfortable, Donald, Jane and Jennifer each greeted him with a kiss hello and as we did in previous days, we sat around our father's bed talking with him and with each other.

From my phone call earlier in the day, my family knew about the changes in Dad's condition and that I thought Dad was close to death and might die soon. They each seemed to understand the seriousness of what I said and appeared calm.

Around supper time Jane left to pick-up her younger children, ten-year-old Rebecca and nine-year-old Robert John. Before leaving she kissed Dad goodbye and explained she would be right back. When Jane left, Donald mentioned being hungry and decided to drive to a near-by restaurant and order take-out and come back to be with Dad. I was watching Dad and when Jane and Donald said they were leaving, I suggested they not stay away too long. They knew what I was telling them.

I knew I was not the only one who wanted to be with Dad when he died; Donald and Jane mentioned they wanted to be here. Dad's condition deteriorated throughout the day and I was concerned that when Donald and Jane left they would not get back before Dad died. With Jennifer and I alone, I stopped worrying about Donald and Jane leaving and paid attention to Jennifer who decided to stay.

Jennifer sat close to Dad while talking with me. I asked how she was feeling about being here with her grandfather. Although her eyes glistened with tears, she said she was okay and not to worry about her. The response is typical of Jennifer, even as a child she had a unique way of dealing with problems. Dad loved Jenny and often teased her by asking her to solve silly questions just so he could enjoy watching her think. Sitting next to Jenny and watching her looking at her dying grampie's face, I wondered what she was thinking, how would she deal with Dad's death, and how would she live with this experience in the years to come? Jennifer appears more mature than others her age, and I worried that she would keep her grief feelings too much to herself and perhaps conceal problems.

At 6:15 p.m. while Jennifer and I were talking, the rhythm of Dad's breathing changed. The quiet stillness of my father's room was overwhelmed by the usual ordinary sound of a singular loud prolonged inhalation followed by a loud and prolonged singular exhalation.

The new sound grabbed my attention. Waves of adrenalin raged through my veins and I panicked. I knew that sound and I knew what it meant! I raised my voice "*Jenny, Grampie is dying! He's dying right now!*" I hurried toward the window and continued pacing and questioning "*Where did Donald go for supper?*" I checked my watch "*How long has he been gone? He wanted to be here!*" I touched Dad's wrist, checked his pulse and continued ranting "*I hope Donald and your mother get back here in a hurry. Time is running out!*" Jennifer watched in quiet confusion as I lost my usual composure. After days of trying to prepare my family for Dad's death, it was *me* who is having problems.

During the end-of-life process a variety of complex interconnected events occur at different times affecting the dying in various ways. As the patient's condition deteriorates and death draws closer, individual family members respond to the final crisis of death in ways that are difficult to understand or anticipate.

I worked with families in long-term and palliative care who appeared calm throughout the duration of the dying process and became irrational when death occurred. Whether or not the death was anticipated was not always a significant or reliable reason for such grief behavior. In my experience, unexpected grief behaviors were influenced by issues outside the dying process that the health care staff had no knowledge of, such as my grief reaction to the absence of my brother and sister when our father was dying.

Donald walked in the room with his hands full of stacked take-out boxes. I hollered to him *“Get rid of that stuff. Dad is dying right now!”* Responding to the seriousness in my words, Donald tossed his food in a heap on the floor and hurried over to be close to Dad.

For the final moments of Dad’s life, Donald, Jennifer and I each had the opportunity to kiss him good-bye and say how much we loved him and that he would be missed. There were no sudden movements and no final frantic attempts to revive Dad. We did nothing to interfere with his death. The three of us stayed close to Dad and we caressed his already cooling skin with our finger tips. We said our good byes and witnessed his peaceful leaving.

When health professionals succeed in establishing close relationships with grieving families and dying patients, they are able to observe the signs and symptoms that occur as death draws closer. Short of being able to predict the precise time of death for a grieving family, an experienced Palliative Care nurse or physician can often tell those who wait at the bedside an estimate of time before death occurs.

With this sense of time left to spend together with their dying loved one, final death preparations and conversations might still be possible. Families can take advantage of this opportunity to either do or say the things they avoided in the past. Having this ability to finalize a relationship before death occurs leaves those who grieve more able to achieve their own peace with the type of final good-bye they desire.

My hand was resting on Dad’s chest when his heart stopped beating. Through my tears I checked my watch and was shocked hearing my own voice call out the time of death as 6:35 p.m.

I am trained to record or register all important or significant events by the exact time they occur. When my father died, no one was more shocked than me when I checked my watch and marked out loud the time Dad died. I was embarrassed by my behavior when I saw my brother and niece's confused expressions and tried to apologize and explained that *I was sorry, that I was trained to do this*. I felt insensitive and hoped that they believed me.

During the delivery of patient care health care professionals are responsible for recording the exact time when significant events such as birth and death occur. The rules of record keeping, time and timing are the legalistic characteristics of the codifying rules bound by and required for participation in a modern bureaucracy (Fox, 1989). I knew that some time on that night before going off duty, one of Dad's nurses would open my father's chart and write the words patient expired and register the time 6:35 p.m.

Moments after my father's death, I realized I did not inform the nurses that Dad had died. They would need to contact Dad's physician so he could visit and pronounce Dad dead, and complete his death certificate. The certificate of death is a legal document certifying the details about why, when and how my father died. Starting to stand up to leave my Dad's room I thought out loud "*I will tell them later. I know what time Dad died. Right now it is more important for us to sit together and be with our Dad.*" Donald and Jennifer and I sat behind Dad's closed door crying and touching him and telling him how much we loved him. I kissed Dad's cheek and whispered "*I love you Dad. You take him now, God.*"

When Dad died the colour of his skin changed to resemble fine, white porcelain. Though his facial expression was peaceful, the essence of life disappeared leaving his body's



presence flat as if deflated and hollow. Dad's eyes were open slightly and because of the stroke the right side of his mouth drooped.

I tried to adjust the position of Dad's head on his pillow and close his eyes. I wanted our father to look less dead and more like he was sleeping. I saw dead bodies before, but this was my family's first experience. I wanted to make certain looking at Dad would not frighten them.

Since my father's death, I spoke with many bereaved sons, daughters, wives, sisters and husbands who are haunted by the memories of how a loved one looked *after* dying. Often these memories were associated with hurtful feelings of regret. Regretting that they *had* visited their dying loved ones in their final days. Without exception, the recollections of the end-of-life events were vivid and were retold in scrupulous detail regardless of the length of time that lapsed since the death occurred.

With these grief survivors, the memories of what they witnessed now overshadows many of the positive recollections of love and affection that once brought them comfort. Their memories leave them to grieve not only the loss of the life of their loved-one, but they also grieve the loss of an opportunity to remember the deceased as they were in healthier times instead of the unfamiliar face of death.

According to Frank (1995) these stories of illness are not the illness itself, but it can become the experience of the illness (or death). The stories of these primary witnesses are personal accounts of powerful truth and desire that have the capacity to shape perceptions of numerous experiences over time.

Recognizing the potential lasting impact of these types of troublesome memories on the grieving experience of those who mourn, it is essential for families to be better informed regarding the complexities of the dying process. In-depth, appropriate dying and death education would help prepare grieving families to cope with the visual experience of witnessing the physical wasting away and virtual disappearance of their dying loved-one's familiar physical appearance at the time of death and after.

Nurses are trained to care for the patients after death. *Post mortem* care includes the preparing, the labelling, and the transporting of bodies to the morgue (Fox, 1989). The dual purpose of after-death care is to: 1) prepare the remains or the body for family members to view for the final time before going to the funeral home; and 2) to prepare the remains to go to the funeral home.

In the past when I prepared a patient's body for their next of kin to view, the family were not present. In the absence of next of kin, I carried-out the necessary after-death care away from the watchful grieving eyes of the deceased's loved ones. This time, such was not possible. Donald and Jennifer remained in the room while I moved around Dad's bed making subtle changes to his appearance.

Dad's door opened and Jane walked in and for the first time was face to face with the reality of Dad's death and the difference in his appearance from when he was alive. I stood helpless and watched my sister's face as she looked at our father lying dead in front of her. I tried to make Dad look like he did before Jane returned so that the memory of seeing him would not haunt her recollections of this time. But, I failed. I will never forget the pleading defeated sound of her words, "*Oh my God, poor Dad, he just looks dead!*" The sound of

Jane's heart breaking words filled the empty spaces of the room. Overwhelmed by what she saw and the loss she felt Jane put her head on Dad's shoulder and cried.

Before Jane entered the room I believed that I could make Dad look as if he was sleeping. When Jane looked at Dad she saw a very different image and she said so. My sister's experience and her response was another example that made me realize I saw the death experience of our father through the perspective of my nurse's insight and experience; my experience of witnessing Dad's death and seeing his dead body differed from the experiences of my brother, sister and niece.

As a nurse, my father's dying and death experience emphasized for me the need for health professionals to never forget the routine lived experiences of nurses and doctors that set our understanding apart from others. In order to support grieving patients and their families, it is crucial for health professionals to at least attempt to understand the experience of dying from the perspective of others and make this significant life changing death experience meaningful for grieving families.

Our sense of loss overwhelmed each of us. Donald, Jane, Jennifer and I sat together stunned and motionless and cried until we thought we could cry no more. I left the room to inform the nurses Dad died at 6:35 p.m. and we were going to stay with our father awhile longer and I would come back and tell them when we were ready to leave. They understood our family's need to stay with Dad, and informed me they would keep other people from disturbing us.

Thirty minutes later when we left, we each kissed Dad and told him how much he was loved. Although we knew Dad was dead, leaving him alone was difficult. Jane made me

promise the nurses would come and stay with Dad when we left. I shared Jane's concern with the nurses and they understood. Even in death, our father's frail body solicited his children's deep desire to be with him.

We were moving like stone ghosts through the hospital's empty hallways when I explained my need to go to the chapel and we all went together. Soon the small sanctuary was filled with the muffled sounds of our crying and our prayers. I knelt down on my knees sobbing and praying "*Thank you God for helping me to be here. Take good care of him for us. We did everything he wanted.*"

I have no real memory of being driven from the hospital through the December evening's half deserted streets and up the hill to my parent's house. I am certain of one thing — that less than one hour ago, my life, and the lives of my entire family changed forever. Even the memory of watching my mother place a lingering good-bye kiss on Dad's forehead seemed a lifetime ago. Grief and a persistent sense of purpose filtered my vision. I was suspended somewhere in oblivion until I saw the lighted Christmas tree standing in the centre of our living room window. The reality of tree's presence was startling.

Somewhere in my mind, I knew Christmas was almost here but with everything happening in the last few days, that thought was lost. The feeling of being confused and disoriented was unfamiliar to me; and this sudden awakening was shocking. Until now, I was unaware of how involved and distracted I was. I stood beside the car struggling to compose myself while the voice in my head chanted "it is almost Christmas, and Dad is dead". My heart despised the now forever permanent entangling of these words.

The rush of adrenalin from the emotions of witnessing my father's death was depleted. The heightened persistent anxiety that fortified me since hearing the sound of Dad's breathing suddenly changed. I stood in my mother's kitchen struggling to clear my mind and organize my fragmented thoughts. It was difficult to imagine what I was about to do. In my position as Director of Nursing in geriatrics I often spoke with grieving family members explaining how their loved-one died. After almost two decades of looking into the tear filled, often frightened eyes of those who grieved, I realized how important telling the dying story is and how what is said impacts the grieving process.

When the events of how a loved-one dies are shared with grief survivors, the words describing the death experience take on a particular enduring significance. When grieving family members strive to find personal meaning in an unfamiliar end-of-life experience, *the significance of the narrative* is enhanced. When death is described in an sensitive manner the grieving process is encouraged rather than burdened by the unknown.

Health care professionals who counsel grief stricken family members following the death of a loved-one need to recognize the lasting impact of end-of-life accounts and how they are integrated into the lives of the grieving listener. The circumstances describing how a loved-one leaves this life becomes a *private memory* although *never repeated*, remains preserved in the grieved heart forever. The recollections of a family member's death become cherished narratives that are told and retold throughout the grieving process and beyond, supporting and comforting those who tell their stories and those who listen. Reminiscence is never only of facts that happened, imprinted on the mind "stored and retrieved through links

of association” (Hillman, 1994, p. 41) but is the ritualistic recall of images of the soul and has important potential for grief knowledge and support for those who experience loss.

Regardless of whether the information or the events associated with the death of a loved-one are later shared with others or kept private, it is important the words chosen and the tone of what is said reflects sensitivity, respect and a true understanding for the individual who died and for those who grieve. I had to do this for my grieving mother. I took a deep breath and prepared to tell my mother the story of how Dad died in a manner so that she would know the truth and not feel regret for remaining at home.

Sitting alone with my widowed mother in our family’s living room I described in methodical detail the events of Dad’s death and pieced together his final moments. I explained to Mom that I was grateful Dad showed no sign of discomfort or struggle; that I witnessed many deaths during my years of nursing and I could say I saw few die as peaceful as Dad.

Mom was quiet and then smiled *“Thank goodness you are a nurse. Having you here to stay in the hospital with your dad was a great support for all of us. He would have wanted you there. Your father was always acting silly and telling everyone about you being his private nurse and I guess he was right. Mom’s voice was quiet as she sighed “I guess it is true that the good Lord has a plan for each of us.”*

## Chapter Six - Stories Remembered - Promises Kept

### Personal Reflections - December 20, 1996: The Funeral

#### Personal Reflections - December 20, 1996: The Planning

Dad was dead for less than three hours when my mother, brothers, sisters and I were pulled onto the postdeath treadmill. After days of waiting in the slow but exhausting pace of the hospital vigil, we now had to meet a series of dead-lines, in order to accomplish everything required of a new grieving family. Struggling to regain coherence in our grief, my family supplied the necessary information to record, announce, and legitimize Dad's death.

Upon arriving at my parent's home after Dad's passing, we needed to organize our fragmented thoughts and struggle to compose Dad's obituary. We rushed it down to our small local paper thus ensuring that the notice of his death would make the next morning's edition. Though everyone was exhausted physically and emotionally, we each helped out however we could. Dad's death stunned us and none of what was happening seemed real. Overwhelmed by loss, none of us had time to begin grieving. The purposeful, time-limited, organized demands of the funeral controlled our attention and there was little time for tears.

That evening the phone calls started, and it seemed that each caller had new orders for our family to follow and more details to consider. Time-lines, obligations and responsibilities appeared everywhere, and we were moved along on this relentless, rapid and unfamiliar wave of ritualizing his death. Late in the evening, the funeral director called and in his monotone, sympathetic voice informed us that we needed to be there tomorrow morning and to bring our father's clothes. During my flight home to be with Dad I wrote and had scribbled notes in

anticipation of his funeral. I was glad I did, because there was now no time for thoughtful reflection.

Later that night I prayed and thanked God for my dad's peaceful death and whispered tearful into the darkness "*I love you Dad. I hope I did everything you wanted.*" I fell asleep exhausted, but peaceful in my heart that I loved my father to the very end. I listened to his stories and kept his promises.

The following morning my brother Donald and I went to the funeral home to select our father's coffin. Walking through the rows of open caskets labelled with the names of expensive cars and concealed price tags was a bizarre experience for both of us. We made our decision and over the phone, Mom guided us toward the final choice selecting the casket with the blue satin lining to accent Dad's silver coloured hair. Donald handed over Dad's suit and tie and the shirt that Mom selected to make Dad appear handsome. I stood with Dad's long underwear folded in my arms, and passed them over to the undertaker. Remembering Dad I pleaded with the funeral director, "*Please make sure that Dad has these - I don't want him to be cold. Dad hates the cold.*"

#### Personal Reflections - December 22, 1996: The Visitation - Celebration of Life

At 7:00 p.m., two days after my Dad's death, family and visitors offered their condolences to my mother, brothers, sisters and I and we shared stories about the man we loved. In the funeral home, multiple conversations mixed with laughter and tears as visitors reminisced about their experiences with Dad. The recorded music of Dad playing his banjo at first shocked people but then they smiled. Near the end of the evening when our family was alone with Dad in his casket. I asked Donald to do Dad a favor and "Crank up that music"! And he did. Dad's banjo filled the sedate visitation room and the collection of photographs of



Dad, which we brought, surrounded us. Dad would like what we did for him on this night. Dad once told me he wanted to play his banjo at his own funeral and this evening his family fulfilled that desire.

Family, friends and neighbors came to remember our Dad for who he was to them. While other families shared loving and familiar stories about Dad, his old customers and his musician pals told stories about yet another man. Their remembering of Lorne Hall spoke of a wonderful, and funny, pharmacist and an often eccentric performer, who loved to laugh and make music with his friends. These stories of a life well lived and much enjoyed, slipped into our memories are now part of our own future stories about our Dad.

At the end of the evening standing in front of Dad's casket with Murray, I heard his whispered words honour our father in a private way reflecting his own memories of Dad. "*He was a good dad.*" In his quiet, hesitant manner Murray put into words that which was the most important memory for Dad to hear and for our family to remember.

#### Personal Reflections -December 23, 1996: The Service

Our grieving family followed Dad's casket as it moved slow and silent down the long narrow carpeted church aisle. Retracing the path that each of Dad's three daughters took as new brides on their respective wedding days. St. Jame's is our home church, the one where Dad stood and sang hymns on Sundays and teased us into outbursts of inappropriate laughing. On this day, Dad's family accompanied him into the church for the final time.

For the funeral, the church was overflowing with people who knew Dad and loved him. Long time friends from our childhood came to acknowledge Dad's dying and to share in our family's loss. Squeezing Mom's hand inside of mine I whispered "*Dad would like this!*"

*The church is packed.*" My eyes returned to the casket and I visualized my father inside. A few feet away from where I sat, my dead father's body lay cold and silent, ready for the funeral to begin. At that moment I remembered his voice and missed his laughter.

In September 1996 six months before his death, during a conversation with me about his funeral, Dad intimated that he saw a funeral as an opportunity for the community to express respect to the grieving family and recognize the contributions of the deceased. For Dad, a big funeral with lots of people is the truest sign of a person's success and the number of mourners attending a person's funeral indicated how well-liked the deceased was and how much they would be missed. Taunting me as only he could - Dad shared his funeral wishes. *"You know Sanie, when I die I want a big funeral. I want the church to be full of people and I want everyone to miss me — and to feel bad."* Dad laughed, but I knew he was being honest. He needed to feel his life was valued. He wanted to be well remembered and well missed

I never appreciated funerals. Before my father's death I had little appreciation or understanding of the funeral ceremony or any of its related practices. Aside from their usual religious connotations, I viewed funerals to be emotional rituals that served no other purpose than to prolong the anguish of grieving loved-ones. I felt so strong about this that I shared my feelings with my family and I informed them that when I died I did not want a funeral.

According to research (Faifel, 1977) any practice which evokes strong emotions, develops positive or negative attitudes in people. Funerals are such a practice and it is therefore normal that peoples' views are polarized regarding funerals. Prior to my dad's funeral, I had a negative attitude regarding them but my grieving process shifted that attitude.

Since the death of my father, I have a better understanding of funerals, for as a grieving daughter I experienced my own parent's funeral. I am more accepting of the role that the funeral service plays within the grieving process and I am interested in understanding more about the planning of funerals and how people arrange the ceremony to make it meaningful to themselves and to their families. As a palliative care instructor I ask students to share the first memory they recall about funerals. Their impressions involve minute details describing all aspects of the experience. Similar to my funeral memory their recollections remain vivid. The rememberings became part of their grieving process and the funeral enhances the memory of the deceased.

Ten years ago, while attending the funeral of a dear friend's father. I began to realize something unusual was happening. The Mennonite funeral service was uplifting and celebrated the life of my friend's father. His name was mentioned with great love and respect. Family members, friends and neighbors shared humorous stories of his wisdom and strength and people grieved his loss through tears and laughter. The funeral was a comforting experience for me and the memory of that day later influenced the plans my family made for our father's funeral.

Our family organized the entire funeral so that those in attendance would know who Dad is, how much he is loved, and how very much he will be missed. A quartet sang Dad's favorite hymns and the eulogy related many of his stories. On that afternoon both laughter and tears filled the church and everyone remembered our father. As a family, we wanted Dad to be remembered as he lived, not as a nameless, spiritless old man dressed up in a suit and lying in a box. We wanted everyone to remember our father's life and the gifts he left us. Our father

was my mother's husband; he was our Dad; he was a Grampie; and, he was a friend. He was also a banjo player and a pharmacist. Most of all, he was a lover of his family and we knew that.

Lamars opinion (as cited in Feifal, 1996) indicates that funerals are an experience in which "to express honest feelings and accept the community support that is freely offered" (p. 237). My father would agree. Dad enjoyed any reason to gather with his musician friends for an evening of good food, music and friendship. For his funeral, we filled the church basement with his friends, good food, and the sound of Dad's own banjo playing. We also had photographs of him enjoying his grandchildren, playing his music, and spending special times with his family. This gathering celebrated Dad's life and although it was difficult for us, it gave us comfort to celebrate him and his life. Dad once spoke to me about his funeral and he was excited thinking about his friends remembering him in this way and he smiled in gleeful anticipation of what that moment would be like. *"It'll be a real jam session, hey Sanie?"*

After Dad's funeral, our family and close relatives returned to my parent's house to talk about Dad and of how he would enjoy the personalized attention his funeral received. Dad would smile knowing that several small gifts and family mementoes were tucked into his casket to accompany him on his final journey. Pictures drawn by his grandchildren, an unused banjo string, two shiny loonies, and my gift of a miniature red wagon had been placed. Pieces of his life were placed beside him so that he would never feel far from those who love him.

Despite efforts to have a celebratory funeral, it was a difficult time. On this afternoon, our family's grief was public as we each left the safety of our homes and the freedom to express our loss as we needed. My mother, brothers and sisters, their spouses and children

moved our grief into the public domain and into the societal mourning practices encouraged by the protocol of the funeral and the Christian church. It was for each of us to attempt some level of social and colloquial interaction with the community members at a time when our emotional loss was recent and our energy levels low. Numbed by our grief we did what we needed to do knowing that we were fulfilling Dad's wishes.

Outside the walls of the old vine-covered church, the traditions of the pre-Christmas rush passed by my family. While inside sitting with our arms interlinked, our heads resting on one another's comforting shoulder, and we grieved. Out of step with time and place and overwhelmed with grief, we struggled to survive our terrible present. The future without Dad was still an unreality.

On the day of the funeral, December 23, following the service, our family entered the church foyer as the pallbearers wheeled Dad's casket close by me. I reached forward and my finger tips brushed against the casket's smooth surface as they carried it from the church and placed it in the back of a polished black hearse and disappeared down the street.

In Truro, anyone who dies after December 1, cannot be buried because of the frozen ground. So, Dad's casket was taken from the church, transported to a vault located in the middle of a large community cemetery and stored there until late spring. In May the funeral director would contact Mom and notify her of the date for Dad's burial. Family would then choose to either attend or not attend his final interment.

Before Dad's death, I had no reason to know about the winter burial in our town and I heard about the spring interment policy only two days prior to the funeral. Even then, the significance of Dad not being buried on the day of his funeral did not touch me until the

moment of the casket was wheeled by. With Dad not being buried, the feeling of things left unfinished and of things yet to do were constant. I was unable to feel any sense of “finality” (Faifel, 1996, p. 242) and this uneasiness persisted until spring when his body was interred.

I heard about the term *finality* as it related to grief but before experiencing my own grieving I had no idea how enduring this experience is. Much like my experience with anticipatory grief, I now believe that neither psychological state receives the consideration and understanding that they require.

Since Dad’s death, I spoke with several grieving family members who are stuck psychologically because the finality of the death has been denied through various circumstances. Their thoughts, conversations, and energies remain focused on what caused the unsettled feelings and the struggle to find a resolution for these sensitive and negative emotions. The ramifications of this type of expressed consequence of grief are intensified when decisions regarding the death were made without their knowledge or involvement. A young palliative care student shared her story of how her family chose not to inform her of the date of her grandfather’s funeral in hope of protecting her feelings. Two years later, she continues to feel unsettled and angry. She has difficulty concentrating on her studies and wants to confront her parents but is unable to. The nagging memory of not attending her favorite grandfather’s funeral has affected her ability to grieve and also her ability to live her own life.

Watching Dad’s casket leave the church without his family accompanying him seemed wrong. Although death separated him from us, the removal of his body from the church was a

true “separation of the dead from the living” (Faifel, 1996, p. 237). I waited for the feeling to pass, but nothing changed until Dad was buried. Only then did I feel some sense of genuine peace.

So, I waited for spring, along with my family, to bury my dad.

Personal Reflections - May 12, 1997: The Burial

May 6<sup>th</sup> This afternoon Jane called to tell me Dad was being buried on May 12<sup>th</sup>. She thought I would want to know but wondered if I felt I needed to come home this time. I listened as my sister discussed the schedule for the interment and I was shocked by my response to what she was saying.

Suddenly I cried, and then sobbed. Within seconds my grief over Dad’s death was fresh and raw again. My feelings of loss were as hurtful as they were the first time. I was not prepared for this. Before my conversation with Jane, I too thought I would be alright not attending the burial. I was with Dad when he died and I thought that experience was enough to ensure for me a sense of peace about Dad’s death. It was not. I needed to be home, once again.

My reaction is not uncommon. Grieving family members are often confronted by emotions they thought were long over. Whether intentional or unconscious, many people associate the process of grieving with a narrow frame of reference related to the time or the calendar date on which the death occurred rather than including the possibilities of anticipatory grief or extended grief. Supporting the perception that the emotional impact of grief lessens with time and once over never reveals itself again.

As a grieving daughter who experienced a strong grief reaction months after the death, I have a different understanding of, and sensitivity to how overwhelming such unexpected emotions can be. This insight contributes to how I care for the grieving needs of my family and friends and it helps me to understand my own feelings whenever a special event reminds me of Dad.

This experience brings me insight as to how grief emotions can reoccur at anytime and influences my role as a palliative care instructor. I now teach students to be watchful for the depth and breadth of grief experiences and the need to recognize how unsettling such emotions can be.

Travelling home on May 10<sup>th</sup> was far less fearful a journey than my December trip. This time there was no anxiety, no uncertainty. I knew my Dad was dead and was no longer suffering. I flew home to join my family so that we could once again show our love and respect for our father. I was angry about the spring burial policy but now I am grateful. I needed the four months to prepare myself to say goodbye.

At two p.m. on May 12<sup>th</sup> my mother, brothers and sisters, and their spouses and children along with Dad's own brother and sister gathered at the cemetery for his burial. As a family we made our father's internment something as meaningful for us as it would be for Dad and to reflect upon who he was. I wanted Dad's burial to be different from those I had attended in the past.

Living in Alberta I have the opportunity to meet and befriend people from various cultures, where beliefs and practices differ from mine. In the past eleven years, we supported



each other through the grief of losing parents and by sharing our private grieving experiences we learned from each other. We discovered what gives us comfort and support in our loss.

Listening to my friend's stories about their grieving practices helped me be more confident and comfortable to change some of mine. On my flight home to Nova Scotia, I thought about what type of experiences my family could integrate into our father's burial service to reflect his life and represent his relationship to his family. This was a burial. A family burial. We must do it properly.

I grew up attending both the Presbyterian and United Churches. I sang in the choir and I witnessed a number of funerals and burials. On a few occasions the name of the deceased was used so often that I wondered if I was at the correct funeral. Dad and I attended one such funeral and Dad suggested "*Sanie you should have taken a better look at the remains to make sure we are in the right church.*" The personal essence of the deceased was absent from these formalized rituals.

However, this practice is changing. There is a growing desire for grieving patients and families to participate in the decisions associated with their end-of-life experiences in all facets of the visitation, funeral, and interment. People want to present their voice, their unique grief experiences and losses in a personal manner. By personalizing funerals and interment practices grieving families have an opportunity to "fill those times with meaning" (Frank, 1995, p. 20) and express grief as they choose.

When my family speak of Dad's funeral and burial we are able to remember the wonderful contributions we each made that day. Our ability to express our relationship with

Dad in such a personal manner helped us celebrate his life and lessen what we lost by his dying.

The day before Dad's burial, my sister Jane, Mom, and I spent the day together driving to the coastal town of Tatamagouche where Dad spent his childhood playing on his uncle's farm and dreaming of having a shiny red wagon. During the day, we visited Dad's favorite places and we shared stories about him. We laughed and we cried. We remembered his outlandish sense of humor and his love of life, and we felt blessed. We walked along the beach where Dad played as a boy and we collected sand, driftwood, and sea shells to place in his grave.

At the burial my youngest sister, Lisa shared a special poem she selected to read aloud for Dad. His five grandchildren placed red roses on his casket and Lisa's three year old daughter Natalie, gave her Grampie a small chocolate bar. Before the casket was lowered into the rectangular cavern each of us spread sand around its perimeters, hoping that some day, years from this day, the beach sand we sprinkled in Dad's grave will become one with him and that he and his beloved Tatamagouche will be together once again.

## Chapter Seven - Lessons in Grief

### Journal Entry: April 9, 1997: Thoughts for the Future

Grief is for the living.

When we realize this, it then becomes crucial that the decisions we make inevitably are the same decisions that will help console us in our survival of the loss.

The choices we make must bridge the gap between the needs of the dying and the enduring needs of the living.

### What Grief Has Taught Me

Before my father's death I had no true understanding of grief and its power to influence my life. I knew only the written descriptions that others authored. When I read the words describing the terrible pain and the loss, the descriptions were just words.

Since Dad's death, I learned that no matter how many books I read, or how many stories I listened to from those who grieve, I would not have understood what grief is or what it feels like without experiencing it myself. Knowing grief is personal and life changing.

I never experienced emotions so powerful or as overwhelming as those which my grief generated. The sense of being out of control and of being controlled were distracting and frustrating. In the first few months, no matter how I tried to refocus and regain some degree of mental clarity it was impossible. Physically, I was tired and listless. I wanted either to sleep all of the time or I could not sleep at all. My mind and body were separate, and I lost interest in most everything. I needed comforting and nothing helped. I felt empty.

Grief gave me a new vocabulary: I spoke the words of pain and loss, before Dad's death and I heard those who grieved use the words describing their "heavy heart". I listened and nodded my head that I understood, but I didn't. Now I do. I too felt the weight of my heart inside my chest as the emotions of loss transformed into a physical weight which bore down with each beat of my heart.

Grief showed me how waves of memories of Dad can overwhelm my thoughts, at anytime or any place and sweep me away in tears. These wonderful memories are by no means upsetting, but I still cry. For months after Dad died, I did not read because I could not concentrate or remember. I knew I was not going crazy, but there was nothing I did that made me feel better. I felt most comfortable being alone and remembering Dad.

Unfortunately, my desire to be alone with my cherished memories of Dad made others uncomfortable. I craved privacy at the same time my family and friends thought I needed their company. Everyone talked to me but avoided any mention of Dad's death or even how I was feeling. My stories of grief were interrupted. I was encouraged to change the topic, to talk about nice things, to move on: to accept my father's death, and to get on with life. Some went so far as to look confused at the deep sense of loss I felt over the death of an 80-year-old man. Others just asked "*You mean you've been in Alberta since 1988 and you still feel that close to your father? And he was how old?*".

The people who asked these questions or made these comments made me angry. My first reaction was shock that they would even say such a thing. Then, I got very angry, quiet, and agitated. I wanted to scream "*You didn't know my father! You didn't know "us"*"

*together! . . . . You don't know how much I loved him and so what if he was almost 80, what difference does that make?"*

People acted as if I was being unreasonable grieving the death of my father as much as I did. They decided grieving for anyone elderly is somehow misplaced or unnecessary. Their attitude devalued my need to grieve and it devalued my father based on his age. Both attitudes were frustrating and hurtful.

I realized that the majority of people I spoke with about my feelings of loss did not want to talk about grief. Their uncomfortableness talking about such mortality was apparent from the beginning as they struggled and ended the conversation. Many people silenced anything dealing with dying, death and grief because they wanted pleasant discussions.

Modern society *separates* itself from dying and discourages any opportunities to talk about the feelings of loss that follows a death. People spend an inordinate amount of interest, time, and energy in avoiding the certainty of death. The feelings many people have regarding mortality and grief are considered to be negative emotions and therefore something to avoid.

Despite my extensive reading about grief as part of my graduate work and my 27 years of involvement with geriatric and palliative care. I was unprepared for the raw vulnerability I experienced in my own grieving. I felt that my family was also vulnerable. I feared that death or other sorrows would touch us because we were no longer intact or whole. This apprehension gave me a different insight into the meaning behind the hymn's words, "Will the circle be Unbroken?" Before Dad's death I felt that the protective shape of the circle kept my family safe. With the circle broken, my sense of security disappeared. I feared the consequent

changes of our loved one's death and their effect on the lives of my mother, brothers and sisters.

Part of my grief response to Dad's death was my fear that home would never be the same. I feared that the loss of such a dynamic father and patriarch would destroy the unique closeness of our family's home environment, family conversations, and our desire to remain close. This apprehension was more than just the fear of change; it was a deep emotional and psychological sense of not knowing what life would be like in the future for all of us. As the eldest in the family, I had a real need to help the other members of my family survive this terrible loss and regain their feeling of being *at home* again but I had no way of knowing how to achieve this lofty goal. I had no way of knowing how to deal with it on my own. As a family, we had to find some way, some how to make home feel like that special place again.

Grief transformed my life in many complex and unfamiliar ways. I anticipated and recognized some of my grieving experiences as those which others have also experienced. But other experiences were complete surprises. With each day and with each new or unexpected emotion, I learn more.

I now discriminate between grief and grieving. My father's death made me look at the two as linked, but different. I can never interchange these two words as I did so many times in the past. I now describe *grief* from the perspective of *feelings*, both emotional and physical, while *grieving* as the process survivors encounter to overcome a sense of loss. These are the routine practices, the prayers, the remembering of anniversary dates of the death, or of the birthdays or other milestones, listening to their loved one's favourite music, the talking out loud to the deceased, the lighting of candles, and the emotional writing in journals. Grief work

is anything that we need to do to survive and to remain healthy while trying to regain our sense of normalcy.

I am now familiar with the meaning of the phrase the heart keeps a calendar. This describes those days when for some reason, unaware to my normal sense of logic or usual way of remembering, when I feel sad or down or distracted without understanding why. I was surprised to realize that without exception, the significance of the date, that my heart kept track of those special days. I responded to the feelings associated with the times my heart remembered.

When I reflect on loss and realize the power of grief, and its ability to affect our lives at will, I also understand how fortunate I am. Unlike many people, I am able to grieve without feelings of guilt and regret over my father's dying and I am therefore free to experience an uncontaminated grief. Comforted by my experience I am unable to imagine what my life would be now, if I was burdened with something I regretted not doing for Dad or not saying to him. The sense of loss is overwhelming enough and I am thankful for everything that contributed to this feeling of peace.

For me, the most significant part of Dad's dying and the resulting grief were my father's stories, explaining what he feared and what he wanted for medical care, if and when he could no longer communicate. Dad told me what he wanted thus enabling me to share that information with his physician and his nurses thereby allowing me and my family to fulfill his final wishes.

All too often families never discuss their concerns about medical procedures involving their loved one with the physician or nurses. The family's fears and anxieties remain unspoken

and are never addressed. When this happens unresolved issues often complicate grief and cause unanticipated and extended problems with anger, frustration, and self-blaming which can continue for years. Although discussions about illness, dying and death are uncomfortable for most people it is important to realize that the information these discussions provide is invaluable to physicians and nurses. It is critical that these discussions regarding medical care choices take place before a health crisis occurs and before the ability of the family to understand is overwhelmed by fear, urgency, and the implications of their choice.

It was difficult for my family to decide to support the "Do Not Resuscitate" order for Dad, but we knew for the last few years of his life what his wishes were. Knowing this helped guide our decision and made it possible for us to be comfortable with our choice after he died.

My Dad's death also gave me an opportunity to witness a care environment that welcomed the involvement of the family into a partnership of care. *This is a relationship that occurs all too often, in active treatment hospitals.* Dad's physician and the nurses made my family feel as comfortable as possible throughout Dad's final days and supported each of us in our bedside vigil. The kind attention we received from the health care staff, comforted my family in an overwhelming situation, and we felt some sense of control in a powerless situation. This facilitating of control helped lessen the possibility that our family's grieving experience would be complicated by guilt linked to our survivor's sense that we stood back and did nothing.

The collaborative attitude of the physician and nurses hold great significance for me as a nurse. In the past my particular involvement with Dad's care was denied. Recollections of



those times are difficult. Though the outcome resulted in Dad dying, I remember this experience as one of mutual respect and caring. My grief is free of the anger and frustration I felt in the past when my role as the nurse in my family was disregarded by Dad's doctors and nurses.

Due to the experience of my Dad's final days, I refocused on the role of teaching philosophies in nurse education. I am interested in the way nurses are educated and how different teaching philosophies influence our ability to care for the dying. I received my basic nursing education from a school of nursing that promoted a Christian philosophy of humanistic, holistic care that valued patient's spirituality. Now I recognize that my education impacted my own grief experience and influences the type of nurse I have become.

When I sat beside Dad that night and experienced the wonderful ever so silent peace that filled his room, I knew in my heart that I was in the presence of something I never witnessed before. When I later realized that my life appeared to have been planned for me to be a nurse and be with him while he died, I felt a strong sense of inner quiet and gratitude and I awoken to my own spiritual sensitivity.

This feeling of peace supported me in my grief and gives me a remarkable sense that God was present at Dad's bedside and that I received an answer to my prayers for his peaceful death. This spiritual experience gave me a deep feeling of security and peace in knowing that what I hoped to be true — is. This experience gave my family a comforting sense of hope that someday we will be together again and that death will not separate us forever.

## Chapter Eight - Epilogue

Wisdom is oftentimes nearer when we stoop,  
than when we soar.

Wordsworth, W. (Cited in Merriam-Webster, 1995, p. 448)

Writing this thesis has been a personal journey as much as an intellectual one.

Reflecting on my father's death gave me an opportunity to appreciate life. Like Frank (1995), I have been all the way to the bottom, and it is solid.

The journey through Dad's chronic illness, his dying and death forced me to re-evaluate my personal and professional understanding of grief. When Dad became ill I feared death; I feared death's ability to take away everything that mattered most to me. Most frighteningly, I was afraid of the loss of my dear father and for my family's life as I cherished it to be. During that time my fear and vulnerability to loss with the inherent finality of death influenced all aspects of my life and intensified as Dad's health deteriorated.

Three years have passed since my father's death. I feel stronger because of my brokenness and wiser because of my journey into suffering. My grief experience helped me move beyond the stages of grief (Kubler-Ross, 1969) and challenged me to consider the offerings of other grief philosophies.

Death cannot be avoided. Because it is inevitable the accompanying grief demands more investigation. Contrary to the seventeenth-century French writer La Rochefoucauld (cited in Mullens, 1997) "that death like the sun should not be stared at" (p. 1), I believe death must be stared at more.

My father's death confirmed for me the critical importance of discussing end-of-life medical treatment preferences and the nature of dying before a health crisis occurs. Grief for the death of a loved one is a significant life experience that is influenced by meaningful understanding by those who grieve of the dying, death and grieving process. As Plato (cited in Humphreys, 1999) suggests to "practice dying"(p. 23).

The grief of losing my father influences my ability to empathize with others who grieve. I now teach dying and grief with my heart as well as my mind and listen as someone who has also suffered. I understand my grief journey has no end but that does not concern me. I anticipate that I am at the beginning of my journey as opposed to its destination.

I thank my God whenever

I think of you

Phillippians 1:3 p. 413

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