



HBRP | Healthy Balance Research Program

A community alliance for health research
on women's unpaid caregiving.



**Snapshots of the
lives of caregivers.**

*“I do it because I
love her and I care”*

Caregiver Portraits

Team Leader: Brenda Beagan

Team Members: Robin Stadnyk,
Charlotte Loppie, Nancy MacDonald,
Barbara Hamilton-Hinch and
Judy MacDonald



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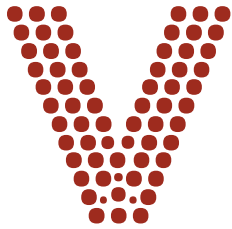
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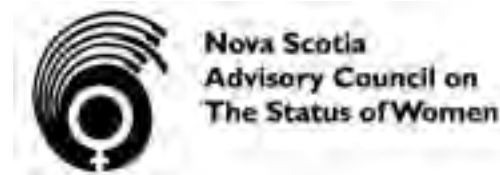


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Introduction



The Healthy Balance Research Program (HBRP) or A Healthy Balance is a five-year Community Alliance for Health

Research (CAHR) grant, funded by the Canadian Institutes of Health Research. It was approved by Dalhousie University Social Sciences & Humanities, May 31, 2001. The research alliance is co-directed by the Atlantic Centre of Excellence for Women's Health and the Nova Scotia Advisory Council on the Status of Women. The program is co-managed by three Co-directors, a Coordinator, and an Administrative Assistant, and includes four research teams, four Equity Reference Groups (ERGs), and a National Reference Group (NRG). The ERGs represent African-Canadian women, First Nations women, immigrant/newcomer women, and women with disabilities. The NRG consists of senior researchers, doctoral students, community group members, and policy makers. The overarching goal of this unprecedented study on caregivers in Nova Scotia is to foster "A Healthy Balance"

for women caregivers' well-being, personal health, personal leisure time, roles in family life, and earnings towards having livelihoods from caregiving.

The HBRP examines unpaid caregiving work specific to the lives of marginalized women in Nova Scotia that lack adequate support systems to regularly care for their seriously impaired care recipients. The care recipients are children, elderly persons, people affected by disability, people that are terminally ill, extended family members, friends, and/or fellow community residents. A Healthy Balance includes attention to caregivers from racialized and cultural minorities as well as geographically isolated populations. One goal of the program is to recommend policies that aim to improve availability and accessibility of caregiver services and programs in Nova Scotia, especially in remote areas and/or marginalized socioeconomic and ethnic minority communities. The research program is guided by four key questions: How does caregiving impact upon women's health? How is caregiving

rewarding? What is demanded of caregivers in their homes? What are the relationships between unpaid caregiving and paid employment?

The HBRP comprises five phases of data collection. Phase #1 consisted of extensive review and analysis of relevant literature on caregiving. Phase #2, led by the Secondary Analysis Team, expanded on previous quantitative research by developing in-depth analyses of existing data relevant to gender, health, domestic responsibilities and other caregiving activities. Phase #3, carried out by a qualitative focus group team (Team Q), added complexity to available data by conducting group interviews with 19 different groups of caregivers throughout Nova Scotia. Phase #4 conducted by the population survey team developed a comprehensive population based survey of caregivers in Nova Scotia. Phase #5, Caregiver Portraits, undertaken by Team P, comprised in-depth qualitative research with 14 women primary caregivers. The 14 micro-ethnographic case-studies provide rich details from the lives of women from 7 different sociocultural

groups in Nova Scotia. Phase #6 of the Healthy Balance Research Program is underway as the CAHR generates knowledge transfer and transformation, much of which derives from the Caregiver Portraits. This document focuses on the results of Phase #5, the Caregiver Portraits.

The Healthy Balance Research Program received ethical approval from Dalhousie University Social Sciences Research Ethics Board, December 1, 2001. The Caregiver Portraits Team launched Phase #5 in year three of the research grant. The Caregiver Portraits are micro-ethnographies that draw directly on the voices and experiences of women actively engaged in caregiving. The participants were recruited through referrals from community-based organizations such as health centres, caregiver support groups, churches and temples, community support services, and women's groups. In addition, Team P distributed recruitment flyers. Some snowball sampling occurred, where one participant referred other potential participants to the study, and the ERGs nominated some potential

participants. Team P hired six research assistants (RAs) to carry out the research, and to recruit participants by approaching and screening caregivers. Many of the RAs had no experience with qualitative research; all we trained extensively. Many had backgrounds connected with caregiver issues, and most were members of the same communities as the participants with whom they were engaged.

The final sample comprises four white women of European descent, two of whom live in rural settings and two in urban areas. Two participants are women who identify as having disabilities, including cognitive and physical conditions. Both are white and live in the city. Two women are African Nova-Scotian, one living rurally and the other in a city. Two women were recruited because they identified as lesbian; by coincidence, one other woman is also lesbian. All three live in the city. Two of the participants are First Nations women, one living on-reserve and the other off-reserve. Two women are newcomers to Canada, having immigrated to

Canada from different countries and having lived in Canada for different periods of time. The women's ages range from their late 20s to their 60s.

Some of the women caregivers are self-employed and they all engage in a variety of activities. However, in all cases caregiving is a top priority. The care recipients include four mothers, three sons, two daughters, two husbands, a father, a grand daughter, a mother-in-law, and an ex mother-in-law. The care recipients suffer from serious physical and/or cognitive conditions such as tuberous sclerosis, spina bifida, or Alzheimer's disease. One participant in the Caregiver Portrait study has been caring for two family members. The conditional nature of caregiving was highlighted during the course of this study. Many of the participants and their families went through changes in circumstances, such as illnesses, injuries, deaths, new jobs, and placement of loved ones in care facilities. Sadly, a few of the 15 care recipients died after the research took place, as did one



caregiver.

Ethical concerns were addressed with participants and care recipients prior to engaging in any data collection. All participants were assured of confidentiality, to the extent they wished, and all signed informed consent for their participation. Each participant was visited in her home several times, over many weeks, at differing times of day, for a total of at least 24 hours contact time. Such visits occurred in accordance with the choice and schedule of each caregiver and care recipient. Care recipients as well as the women caregivers were usually present during these visits. Participants carried out their daily routines while the RAs kept them company as participant observers. RAs kept detailed field notes about their observations.

During some of the visits with caregivers, the RAs also conducted in-depth semi-structured interviews. Interviews lasted approximately one hour each. The interviews were tape-recorded, and later transcribed and analyzed. The six interviewers

inquired about the emotional and physical joys and burdens of the women's caregiving, then posed questions about the moral and ethical implications of caregiving, and finally asked the participants to speak about the institutional services and policy programs designed for caregivers. Where possible, care recipients were also interviewed once, as were other family members of loved ones significantly connected with the caregiving situation, if they agreed.

For the research, the women were given disposable cameras to photograph various moments of their day-to-day activities that best illuminated their experiences as caregivers. All participants gave written consent for us to use selected photos. At the same time, the photos also provided a focus for on-going conversations with the RAs in helping us to understand their lives. All participants, care recipients included, have been given pseudonyms, false names. Other details may also have been altered to enhance their

confidentiality.

This Phase of the HBRP aimed to deepen understanding on the challenges entailed in caregiving as a lifelong occupation. The research also sought to uncover the gendered dimensions of caregiving. The 14 case-studies illuminate similarities and differences among a diverse sample of caregiving experiences. The Portraits illustrate the multiple responsibilities of women primary caregivers in the household, as well as highlight their interpersonal relationships, pinpoint the hassles and cherished moments of caregiving, identify the moral and ethical complexities, and determine how their lived experiences are shaped by service provision, government institutions and program policies. Each woman's story was documented in a 20-30 page narrative. Here we have distilled those full stories into much shorter narratives, aiming to enhance accessibility of their stories, while still retaining some of the flavour of their experiences.

Throughout these abbreviated

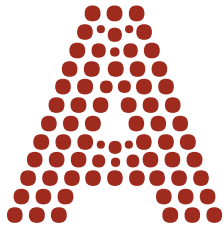
Portraits, we have tried to bring to light policy and service implications. The lives of these women caregivers, and the loved ones for whom they provide care, are directly affected by the programs and services made available to them. There are many instances of inadequate services, services provided in ways that unintentionally make them less useful, and complete lack of awareness of available services that could considerably ease the load of caregivers. At the end of the 14 stories, we have included a summary of policy-oriented findings and recommendations gleaned from the narratives of these 14 women who so generously shared with us their time, their insights, and their experiences.



Amara's Portrait

"[Caregiving] is the only thing that I've done since I came to Canada."





Amara is a sixty-year old immigrant woman from Lebanon who lives in Halifax, where she is a full time caregiver to her husband, Jonathan and their adult daughter, Rubaa. Through her generous participation in this study, Amara shared her experiences and feelings about being a caregiver, the role of religious faith in her life, and her interactions with the Canadian health care system. Amara is an optimistic woman who exhibits tremendous courage and strength as a caregiver. Amara credits her Catholic faith as her primary source of stability, and throughout the research period Amara spoke of her firm belief in Fate, or Nassib: “Que será, sera” (whatever happens it is meant to be). Amara believes that her acceptance of God’s will in regards to her role as a caregiver has provided her with great strength in the face of hardship, and the ability to dedicate her life to her family.

Sitting on the chesterfield listening to Amara’s story, one can envision

her as a young, vibrant woman, full of dreams as she started a family in a foreign country. Shortly after they were married in Lebanon, Amara and Jonathan migrated to Halifax to be with Jonathan’s family. Although they did not have higher education, in Canada, Jonathan and Amara made use of their strong entrepreneurial skills to become self-employed, and learn English from university students who rented rooms in their home. Rubaa was their first child, born in Halifax when Amara was 21 and Jonathan was 43. At three months of age it became evident that Rubaa’s physical and mental development was severely challenged, and three years later she was diagnosed with brain damage. Despite strong predictions that Rubaa would lead a short and unfulfilling life, Amara’s dedication to care for her daughter and provide her with an enriched environment has enabled Rubaa to surpass all medical expectations. Rubaa is now an energetic thirty-nine year old woman with a solid build and a gentle voice. Rubaa lives with Amara and Jonathan in their Halifax home. She requires assistance to get dressed and

bathe, but she can feed herself, do crafts and help with simple household chores. Rubaa has limited verbal communication abilities, but she is able to speak through short series of questions and answers. While she is unable to tell the time, the days of the week, or months of the year, Rubaa is aware of the seasons by festive celebrations.

Amara’s role as a caregiver to her daughter has been intensified by her commitment to provide full-time care to her husband who was diagnosed with Lewy body dementia and Parkinson’s Disease seven years ago. Amara’s interactions with individual health care personnel have been positive in relation to Jonathan’s illness, but frustrating experiences with homecare services ultimately led her to become his full-time caregiver. Amara’s most troubling interactions with homecare services stemmed from the rushed service and inconvenient rotation of workers.

... they used to rush him up at 8 o’clock in the

morning to give him bath. By 8:30 they give him his breakfast, by 9 fix his bed, 9:30 they had to leave, and every two or three days he threw everything up, so I end up doing more work, because they're rushing him...most the time, the workers, they would rush, and rush, and rush.

Jonathan was originally assigned a specific homecare worker, which maintained his comfort level and permitted Amara to leave for her errands as soon as the worker arrived because the worker became familiar with Jonathan's routine. However, the service provider then assigned two workers to rotate on a weekly basis, and the system continued to change until eventually a different worker came each day, an inconvenient schedule that only added to Amara's workload.

I wasn't very pleased with that system in the end. Like

I know one time they used to send me two women, they would rotate...every two or three days, one of them will come. Then year later they started change, and year later they start to send me every day a different one. They don't know anything about his condition, what he eats, where his clothes were, what they're supposed to do for him, so I end up, that's how I end up doing things with him more, and I am not supposed to be doing that. The idea is to help me.

When Jonathan was admitted to the hospital for seven weeks, homecare services were suspended and there were no staff available when he returned home. After several weeks of trying to arrange homecare that would provide her with temporary relief from her caregiving duties, Amara decided

that Jonathan would receive the most attentive and regular care from her directly.

I have a lift and I taught myself, day after day, you know. Because you learn everyday, you learn how to deal with him, and how to do stuff...Now I know how to deal, how to dress him, undress him, and wash him.

Amara now spends each day caring for her husband and daughter, balancing their needs for physical and emotional care on a delicate scale, while remaining in tune with her own needs and ability to continue providing care. Amara tends to all of Jonathan's personal care from the moment he wakes to the time he is put to bed for the night. On a typical day, Amara will wake up early and shower before waking Jonathan and feeding him breakfast in bed. Amara usually has a few minutes on her own to enjoy her coffee and listen to the news when Jonathan naps



after breakfast. She then prepares Jonathan for his bath and cleans him, a process that takes about an hour and a half. With the aid of an electrical lift, Amara carefully moves her husband from the bed to the wheelchair and from the wheelchair to the bathtub. Each day, she follows the same careful procedure to help Jonathan on and off the toilet. Amara will wash and change Jonathan three to four times a day, and each morning she shaves his face and brushes his teeth. When necessary, Amara trims her husband's hair and nails, always taking great care to be gentle and patient. Once Jonathan is prepared for the day, Amara gives him his medication and helps him back into his chair. Every morning when Jonathan rests in his chair, Amara changes the sheets on his bed and plans the rest of their day. Daunting though these tasks may be, Amara is deeply committed to caring for her husband and feels a sense of enjoyment in maintaining his well-being.

My life is devoted to Jonathan, before it was for

Rubaa. I like to cook and bake and I always wanted to be a mother. That has been my enjoyment in life. Since I was a young girl I always dream to be a mother and house wife. Now I guess I am doing it to the end. That is the only thing that I've done since I came to Canada.

Alongside her routine with Jonathan, each morning Amara helps Rubaa bathe, and get dressed, and prepares her daughter's breakfast. Rubaa's homecare worker cares for her from 10am until 4pm, a necessary service that allows Amara to focus all of her efforts on Jonathan's care. Amara spends her afternoons with Jonathan and usually wheels him to different places around the house, outside for a walk or on the balcony to enjoy the sun. Amara usually has some time to herself in the middle of the afternoon when Jonathan takes a nap, and she often spends this time cleaning the house, doing

the laundry and making the beds. Every evening Amara prepares dinner for her family, including all of her children that live in Halifax. Jonathan usually has dinner in his room, but on special occasions he joins his family in the dining room and Amara feeds him. Amara's daughter usually helps to prepare her father for bed, a lengthy routine that involves washing him, removing his dentures, and putting on his pajamas with fresh disposable undergarments. Amara is very grateful that her children provide her with support, and she feels blessed to have such a close family in Canada.

In addition to the extensive array of tasks that Amara accomplishes each day to ensure that Jonathan and Rubaa receive proper and compassionate care, Amara's role as a caregiver also involves less visible responsibilities; she arranges medical appointments and homecare services, provides them with emotional care and helps maintain their social networks. For example, Jonathan's dementia often causes him to feel disoriented, and during difficult periods Amara will sleep beside

her husband to comfort him.

He needs 24 hour care, sometimes he stays up late, he's up most of the night. So I come down and sleep on the couch beside him ...He worried about the children, whether they had a car accident, or being raped, or murdered, so I'll say "No, don't worry, the children are fine. I'm here, the children are sleeping," So I sleep on the couch by his bed...He hears my voice, he's calm.

Amara's role as a caregiver to Rubaa and Jonathan has necessitated interactions with the health care system for over thirty years. In reflecting on her experiences of health care for Rubaa and Jonathan, Amara tells two very different stories, primarily in relation to her experience as a newcomer to Canada compared with her experience as a settled immigrant.

Amara has been in Canada for almost forty years and considers herself fully Canadian. She believes her experience of caring for Jonathan was unaffected by the impact of migration compared with her earlier experiences as a newcomer caring for Rubaa. Amara raises elements of culture shock, gender issues, systemic racism and discrimination within the Canadian society as having an impact on her early caregiving experience. In discussing factors that limited her ability to negotiate the Canadian health care system when she first arrived in Canada and was faced with Rubaa's illness, Amara highlights language barriers, lack of knowledge of the medical and education systems, and difficulties with cross-cultural understanding. Amara's experiences as a newcomer have led her to develop strong opinions about how the Canadian medical system could improve to meet the needs of new Canadians.

If you could find help for those people who are alone, who are caregiver for husband, or wife, to

give them the break, to fight for them... some people they don't know anything. They don't know how to deal with, they don't know how to ask for help, they don't know who to contact. That is very important to find help for them, because I know when my daughter born, I don't know who to talk to, who to call, how to demand help, and I couldn't understand the news. . . You are ashamed to ask for help, because we grew up you know we have to do it ourselves. That's very important, to help them, to say there is a place where you could ask for help.

Caring for a child with special needs shaped Amara's experiences of motherhood and married life. She often felt divided between her



responsibility to provide care for Rubaa and her responsibilities to her other children and struggled to manage family relations. Jonathan's illness has been a particularly difficult part in her journey of caregiving, as it has caused their relationship and future plans to change, and has disrupted their connection as husband and wife.

You're not looking after your husband anymore, you're looking after a child... you don't expect you husband to get old and sick. I mean sickness could strike anybody, young or old. Yes, but I was thinking my children would grow up. I've been giving them all my life. So when they grow up, it's time for me to give myself the time. And then my husband got sick, so I continue.

Losing her partnership with

Jonathan in caring for Rubaa has further enhanced Amara's dependency on her grown children and limited her personal freedom. However, Amara is content caring for Jonathan and feels that he is grateful for her help, but she often worries about her own health and recognizes that she will not always be able to provide care. Amara tries to keep healthy and regularly prays for strength to care, wisdom to solve problems, and love to be compassionate and gentle. Amara believes that caregiving has increased her capacity for compassion, understanding, patience and strength, and remains committed to caring for her family for as long as she is able.

It takes time, I'm reaching 60 years of age and I don't have the energy like before. What I used to do for an hour, now it takes me two or three hours to do. Especially with a special child, and dealing with a sick husband who needs care 24 hours a day, so it's

very tiring for 60 years. You know sometimes I reach a point where I can't walk, I can't do anything. Yeah but I enjoy doing things, you know I bake, I cook, I make bread, I make supper for everybody. Just part of a busy day.

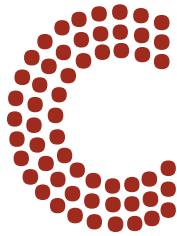
Postscript

In the months following this research, Jonathan passed away in the hospital, surrounded by his family. The first month and a half after his death were especially difficult for Amara, and she still finds herself getting up in the morning expecting to prepare breakfast. She misses his presence and her daily routine. She looks sad and a bit thinner. Amara now spends more time with Rubaa and has had the opportunity to travel outside of Nova Scotia to visit her other children. Amara's strength, faith and family will see her through this difficult time.

Carol's Portrait

But you take on a lot – sometimes more than you really should.





Carol is an energetic and optimistic 60 year old Caucasian woman who is a full-time caregiver for her mother, Anna.

Carol was born in Nova Scotia and currently lives in Halifax close to the house where she and her nine siblings were raised. Carol has been divorced for several years and she has no children. As a full-time caregiver to her mother, Carol's financial needs are met through self-employment opportunities. Carol's mother Anna is 87 years old. Anna grew up in a small town in Nova Scotia, in a family of twelve children. Anna and her husband settled outside of Halifax and raised ten children.

Seven years ago, Anna was diagnosed with Alzheimer's Disease. Symptoms of the disease first affected Anna when she was living with her husband, Richard, an unsympathetic man with a flaring temper. The disease progressed quickly, and it became apparent that Anna and Richard could no longer live independently. Their children collectively decided that Carol would move into their

parents' home to provide the support they required, because the others were occupied with their own families and had less flexibility than Carol. Shortly after the move, Richard passed away. Carol and Anna then moved into a home of their own, and Carol became Anna's "caregiver."

Anna's Alzheimer's is now in advanced stages. She can recognize Carol and her children that regularly visit, but she struggles to remember anyone else. Anna is able to feed herself if the meals are prepared, and she is able to walk slowly by clinging to walls and furniture for support, but weakness in her knees has further decreased her mobility functions. Anna's diminishing ability to think clearly and express herself verbally is the most difficult symptom for Carol to accept. Anna's behaviour is not aggressive, but frequent confusion often interferes in her ability to perform basic tasks.

[I] can leave her alone in the bathroom, but pads go on backwards, on wrong, or inside-out, or

the leg goes to the waist, and ... oh, sometimes she redresses herself at night... I find her legs in the pillowcases, trying to walk with the pillowcase on. [She] puts the shirt over her waist. How she can get the neck of her shirt over her waist is beyond me, but she does! ... this dressing part is not good.

Carol's caregiving consists of an array of physical tasks which necessitate a constant stream of emotional energy, attention, and concern. Whether Carol is making Anna lunch, putting drops in her eyes, blocking the door to prevent her from leaving, or simply asking her mother how she is feeling, Carol strives to keep her mother comfortable and content. Carol is very affectionate with Anna, and often addresses her by her first name, which Anna enjoys hearing. Caring for Anna requires a great deal of patience and unconditional love. For example, during one

meal Anna took chewed up pieces of meat from her mouth and put them in the main salad bowl. Carol reacted with kind humour: “Oh, what’s this? There’s meat in the salad!” Carol’s patience and expressions of affection for Anna were evident throughout the research period, and highlighting the essence of the care that Carol provides.

Although Anna’s home care worker arrives in the morning, Carol prepares all of Anna’s meals. When Anna is reluctant to eat, Carol takes time to encourage her. Every few hours Carol asks Anna if she needs to use the bathroom, and leads her to the toilet. Carol also cares for Anna by picking up prescriptions, administering medication, and driving her to medical appointments. On occasion, Carol and Anna enjoy going out for lunch and short walks together. The following excerpt from our researcher’s field journal illustrates how Carol’s caregiving consists of a constant stream of activity:

During one visit Carol and

I decided work on a jigsaw puzzle at the kitchen table. Anna was feeling well and decided to join us at the table. Before we began the puzzle, Anna let out a cough and Carol commented on how terrible Anna sounded. Carol turned to Anna and said: “I think I’m going to give you some more medication for that cough,” to which Anna emphatically replied: “I’m not taking any medication!” Carol calmly told Anna that some medicine would help her cough, and when she poured the syrup into a spoon and handed it to Anna, she took the medication willingly. A few minutes later, Carol asked Anna if she had to go to the bathroom. When Anna did not reply, Carol

got up and took her to the bathroom anyway. When they returned, Carol asked Anna if she was hungry for a snack. Anna declined the offer, but when Carol offered her a cookie, Anna happily ate the snack. Carol then noticed that Anna had begun to cut a hole in the tablecloth, and she rose to take the scissors away from Anna. Every time Anna coughed, Carol jumped up, held a Kleenex to Anna’s mouth, and said: “Now you spit that up, okay ma? Please and thank you.” Every few minutes, Carol would ask her mother how she was doing. Several times she got up, walked over to the side of the table where her mother was sitting, hugged her mother, and kissed her mother on the



cheek. When Anna's eyes started to close, Carol wheeled her into her room to put her down for a nap.

Carol remains patient when caring for Anna, especially when mother becomes agitated or confused. Anna's disease often causes her to engage in conversations that make little sense outside of her own mind. When this happens, Carol tries to go along with the conversation as though she understands. At times Anna becomes agitated and raises her voice to Carol. Carol has developed a series of strategies for dealing with these episodes, such as giving Anna a doll to hold onto while rocking in her chair. However, there is often nothing that will calm Anna down. Sometimes Carol must let her mother to act out her feelings in a safe environment.

As Anna rarely sleeps through the night, Carol often cares for her mother throughout the night.

It's rare, now, [that] she

sleeps right through. She gets up and she hobbles into my bedroom. And lots of times she'll stay in my bedroom... Some nights she'll come in my bed and she'll go right off to sleep and she'll stay asleep. But sometimes she won't settle at all... She wants to get up. She keeps moving. She plays with the blankets ... And it irritates me because I don't fall off to sleep...

Carol finds being isolated in her home while looking after Anna to be one of the hardest aspects of caregiving.

I'm pretty much confined to my home, you know? ... The world's going on around me and I don't always know what's going on out there.

Overall, caring for Anna involves

attending to her physical and emotional needs in a multitude of different ways. Carol's work consists of specific physical tasks, and a myriad of emotional responsibilities.

That's the caregiving. That's right. I mean, sure it's one thing to care for her by way of preparation of meals, and her personal care or her well-being, but you know, when she needs attention herself, you've got to be there for her. And she requires that!

As Anna's primary caregiver, Carol is responsible for coordinating all of Anna's professional care. Anna receives home care support through two separate organizations, and she is grateful for the respite every morning, although she generally uses the time to buy groceries and pay bills. One of Carol's frustrations with homecare is the lack of continuity of care. For example, Anna often has as many as twelve

different home care workers in a two week period. Each time a new worker comes, Carol spends her own respite time to take them through Anna's routine. Carol also feels that some employees do not make a sincere effort to work with Anna.

We get caregivers in here, home care people, I come home and they say, "She wouldn't do a thing for me! She wouldn't do a thing!" And I said, "Well I have those days, but you've got to change your approach." "Oh I did it all!" I said, "No, you didn't do it all if you didn't win her over."

Carol has created a "personal care book" in which she has recorded Anna's routines, with the intention of helping new workers who are willing to learn about Anna's needs. Carol also feels that the home care organizations are not always willing to be flexible or meet their client's needs, particularly in terms of scheduled

visits. Carol has a list of private sitters to help care for Anna when home care is unavailable, or if Carol needs to leave the house.

Given the amount of time and energy that Carol dedicates to caring for Anna, she feels that caregivers should be paid for their work. Financial support would not only help caregivers supplement lost income, but it would also validate their work.

I feel I work as hard as the next one or I work as long as the next one, absolutely. And don't get anything for it. But I'm not complaining because I chose this, you know? I just chose to do this.

Carol puts a lot of time and energy into caring for Anna. She derives satisfaction from this work and is pleased with the work that she does. With the exception of home care, Carol is content with the services that she receives. She feels fortunate that she lives in an urban centre where services and

amenities are close at hand. An urban location also affects Carol's access to income as a caregiver, as she is self-employed, and a portion of her income is generated through a basement rental unit.

Carol's siblings support Carol in her caregiving work by attending family support meetings at the Alzheimer's Society, occasionally cooking meals, and maintaining the house. Carol makes an effort to keep Anna in touch with her other children, and she encourages her siblings to phone and to visit. Carol feels that her siblings respect her role as a caregiver to their mother, and their appreciation is important to her.

[My family members are] quite pleased with the job that's being done. So, I guess I get my contentment from all that. ... And most of them have all given me a free hand, and a supportive one! ... So I think that's where I get



my gratification.

Carol is proud of what she accomplishes, especially when she receives praise from others. She has taken training courses on Alzheimer’s in order to learn more about what to expect in the future. She strives to ensure that Anna receives loving care. While the day-to-day aspects of Anna’s care can become burdensome, there are also many gratifying times. Every so often Anna will be in a clear state of mind and will pat Carol on the cheek as a gesture of affection and appreciation.

Despite the burdens and challenges of caregiving, Carol remains committed to caring for Anna. Carol’s story exemplifies the reality of two women engaged in the most circular of relationships: a daughter providing full time care for her elderly mother. Carol knows that Anna’s Alzheimer’s will continue to progress, and she has considered the likelihood of eventually placing Anna into an extended care facility. For the time being, Carol will continue to care for Anna and maintain their loving relationship as mother and

daughter. As Carol claims:

*We get along like 2 peas
in a pod!*

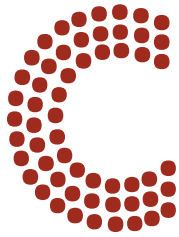
Postscript

In the months following this research, Anna fell, broke her hip, and was hospitalized for two months. Despite Carol’s wishes that her mother return home, Anna’s medical needs were beyond Carol’s most ambitious abilities. Anna now lives in an extended care facility. She requires a special wheelchair and a lift to transfer in and out of bed. Her speech has further deteriorated, but she remains alert. Carol believes that Anna is well cared for and content. Carol misses having Anna at home, but she is glad to have had the opportunity to give back to her mother a few of the “caring years” that her mother gave to her.

Chris's Portrait

"You have to know yourself, how much stamina you have."





Chris is an active single woman in her forties who self-identifies as a lesbian. She lives alone in a basement apartment in Halifax, and works as an administrative assistant for a research organization in Halifax. Chris is a caregiver to her 78-year-old mother, Pat, who has been diagnosed with Multiple Sclerosis (MS). Since Pat currently lives several hours outside of Halifax, Chris provides distant care in the form of emotional support, and physical care when her mother visits the city. Her role as a caregiver to Pat has been challenged by her own physical disabilities, mental health concerns and stressful life events. Chris suffers from lymphoedema tarda, a condition that generates great discomfort in her leg, and she identifies herself as a mental health consumer, diagnosed and medicated for two psychiatric conditions: attention deficit disorder (ADD) and post-traumatic stress disorder (PTSD). Chris explains that ADD makes her hypersensitive to noise, and that she has difficulty with extended period of concentration. The

PTSD is the result of protracted sexual abuse by her brother Tom when she was a child, and is often manifested through panic attacks. In recent years, Chris has benefited from regular therapy and medication, and she anticipates being able to stop her use of medication in the near future.

Chris's mother Pat is 78 years old. She has short curly hair, blue-grey eyes and she wears glasses. Pat is always neatly dressed and appears to be in good health despite the fact that she has had MS for many years. Multiple Sclerosis has gradually affected Pat's mobility functions, and she refers to the progression of her disease as "slowing down." With the support of a metal walker Pat is able to accomplish most of her own personal care and she continues to enjoy her hobbies, although she gets tired quickly. Pat's son Greg lives in Halifax and takes care of her financial matters. Three years ago Pat's husband John died after a long battle with cancer. When John first became ill, Chris provided care for both of her parents, while she remained committed to her paid work and

the completion of her Master's degree in Halifax. Caring for her father was very difficult and affected Chris's emotions, finances and health. After several years of balancing caring for her father, working and finishing her degree, Chris quit her job and focused on caring for her father. Chris also supported her mother through this difficult time.

They couldn't [take care of each other] and each one was absolutely upset about that, and I was, as the daughter, doing things for them that, in a way I felt intrusive. You know I'm intruding in getting in the middle of a very intimate relationship. A husband and wife who's been together 53 years, have this intimacy that you, whether you're a child or not you're just not a part of that and you shouldn't be. But it was

upsetting for them, and it was distracting for me to have to get in the middle of that, and to intrude on that. So each of them felt guilty that I was doing what they felt they should be doing for each other.

Following her father's death, Chris was faced with the financial strain caused by having left her paid employment to care for her father. She was unable to return to work immediately because she needed to arrange care for her mother and support her emotionally.

I had no money, you know. I lived off my Visa for probably three months. I'm still recovering from that, hopefully this summer will put me out of all my debts, I'm hoping. But I'm still recovering from my Dad's death a year and a half ago. Trying to, you know, get back on track

financially.

Chris has continued to provide emotional care to her mother by distance from Halifax. Pat lives in the South Shore with her son Tom who provides limited physical support. Chris is extremely resentful that Pat has allowed Tom to live with her, as Tom sexually abused Chris as a child. Tom was subsequently convicted of a different crime and imprisoned for several years. Chris will not visit her mother and Tom, but every six to eight weeks, Pat travels to Halifax and stays with Chris in her apartment. Chris performs several caregiving tasks in preparation for these visits, such as contacting the Canadian Red Cross and borrowing a raised toilet seat which allows Pat to use the toilet independently. Each morning during their visit, Chris prepares Pat's breakfast, helps with her medication and assists with personal care such as bathing, dressing, and cutting her toe nails. During the day they visit friends and relatives, shop, get haircuts, and do other errands. When necessary, Chris schedules Pat's medical appointments and

takes her to and from the clinic.

Chris's physical caregiving tasks are complemented by the emotional care she provides for her mother.

If anything emotional is going to be shared, I'm the one who's going to hear it. So that kind of care is more... it's both a listening, empathy, letting her blow off, letting her get out her feelings or leaving her home, the leaving that's coming up. And the fears around ending up in a home, all that stuff, I'm going to hear about that. And so that's also my role is to, I think I'm the one who's going to, not counsel her, but hear about her fears and her concerns.

While this distant arrangement is currently manageable, the family



understands that the time will come when Pat requires full-time care. Although Chris feels that her natural role as the daughter is to care for her mother in the last stages of her life, she has been reluctant to dedicate herself as a full-time caregiver. Chris has ultimately decided that she would not be able to live with her mother because she continued to support Tom. Chris also knew that she would not be able to care for her mother and work full-time, and the family could not afford full-time nursing care. Chris also identified tensions that she anticipated would arise if Chris were to bring home a lesbian partner. Chris came out to her mother a year and a half ago, and although they have not had many discussions about her relationships, her mother has reacted fairly well to the news. However, Chris feels that Pat might feel uncomfortable if Chris and another woman were to express physical affection in front of her, and Chris will not adjust her relationships in her home to suit her mother. Chris is also reluctant to sacrifice any

more of her personal life.

For all those years I didn't have[a personal life] in many ways...And I feel that if there is anyway to do some of those things now, before I get old and die, I'd like the opportunity.

Chris has suggested that Pat put her name on a waiting list for a nursing home near Halifax, but Pat has been reluctant to relinquish her independence.

So I've had that discussion with her. I can't do anything and I don't even try to push or prod. I just make sure that she knows her options, and then I leave it. And Pat is completely capable in making her own decisions at the moment.

Through her experiences of caring

for both her mother and father and tending to her own mental and physical health needs, Chris has had a great deal of exposure to the health care system. Her most significant criticism is that services do not work in liaison with one another, which results in a lack of coordination in different patient services. Chris expresses frustration and resentment at being left to put together all the different services from professionals such as surgeons, nurses, family doctors, palliative care, social workers, home care and continuing care. It was out of necessity that Chris took on the role of patient services coordinator and advocate for Pat's well-being.

Over the course of the extensive research period, Chris emphasized three ways in which existing health care systems and institutions could be changed to better accommodate patients and their families through: a well-coordinated system, self-managed care, and a central lending system for adaptive equipment.

Chris is firm in her appeal for an integrated, well-coordinated

system, and suggests “there should be one central spot where all of them connect and come together and are integrated.” During the most stressful times of her father’s illness, Chris was faced with several “disjointed and disconnected” care providers.

I found the biggest thing was that none of these people have conferred with each other much. So I was the one saying, “Oh well you need palliative care.” Okay, so now I call palliative care, and “So where am I going to get all these things?” “Well, you need to call the Cancer Society.” So I was dealing with the Red Cross, Cancer Society, Palliative Care, a social worker at the hospital, the doctors, the nurses, and every one of them would say, “Oh you need to talk to....” So it was never, “I will call for

you” or there was never one focal point.

Chris believes that her family would have been unable to manage such complicated coordination of services for her father, since Pat was quite ill at the time and her brothers did not have the background to know where to go or what to ask. Chris feels that people should be able to do “one-stop-shopping” instead of going to numerous agencies and departments in search of medical support.

There needs to be a well coordinated system, and when you go to approach either home care for support or...whatever the point of contact is...that person should have an information package. They sit down with this person and say “Okay, here is what’s available for you.” So and so coordinates everything from there so

they will know. They will assess your needs, and if you wish this decision will be put in place. These people will all work together.

Chris highlights that her experience as a caregiver would be much different if she and Pat were permitted to manage her care. Chris also advocates for funding for disabled people to employ their own attendants, and for a central lending system for equipment temporarily used by people with disabilities would also be a great resource for those whose need for equipment is temporary or fluctuates over the course of a life with chronic illness.

Chris further emphasizes the need for a caregiver who is not a family member, a belief that stems from her experience of caring for her terminally ill father. Chris believes that Pat felt tremendous guilt that she was unable to care for her husband, and that this guilt was furthered by observing her daughter provide intimate care



that should have been the work of a professional.

I think if it had been a nurse instead of me, I don't think Mom would have cried so often and said, "I should be the one doing this and not you." I don't think she would have said that to a nurse.

Chris manages her caregiving responsibilities, her own health and her personal life by maintaining balance and control. Particularly given her own disabilities, Chris stresses the importance of balance and knowing her emotional needs and limitations.

You know if you don't stay on top your own stuff, and try to make sure your own needs are met too, you're not going to make a good caregiver...Being supportive to your parents but assessing what you

can really do, without going under. Because you have to know yourself, how much stamina you have.

Chris benefits from a strong support network of friends and family who help meet her different needs in light of her role as a caregiver. Chris also receives psychological and spiritual support from her therapist. Despite the difficulties presented by her own health conditions, Chris continues to care because of the love and empathy she feels for her mother, and the rewards she receives from her role as a caregiver.

I love her, and you know we can have a lot of fun together. I really like helping her, I like making her life better, I like to make her happy, I get joy out of giving her joy...So I do it because I love her and I care. Both because she's my mother and I'm

a person who cares, just cares about her.

Diane's Portrait

"There's not enough help."





The following portrait details the complex caregiving work undertaken by three members of a Halifax household: Diane, a 60 year old woman with Multiple Sclerosis (MS); Vicky, Diane's 36 year old daughter with High-Functioning Autism; and James, a 42 year old friend of the family with multiple disabilities, who has lived with Diane and Vicky for twenty years. In considering the lives of Diane, Vicky, and James, the metaphor of a tripod comes to mind. Each individual represents the three legs of a tripod, each holding the other with an ultimate balance, while facing the ever present danger of falling if one leg tumbles. The balance they create is both essential and precarious.

Diane was born in Saskatchewan as the youngest of three children. After she was married, Diane and her husband moved to Eastern Canada and had two children, Emily and Vicky. Diane and her husband were divorced twenty years later, her ex-husband returned to the West coast. Diane and her ex-husband remain in

contact. He was recently diagnosed with cancer. Their daughter Emily lives on the West coast with a family of her own. Diane was diagnosed with multiple sclerosis (MS) over thirty years ago. MS is a chronic, often disabling disease that attacks the central nervous system. During the mid-1980's, Diane experienced a major MS attack and the disease has since deprived her of many functions. Diane now uses a powered wheelchair, and requires assistance to bathe and use the toilet. She has lost the function of her right arm, which has limited her ability to enjoy her favourite activities, such as peeling potatoes, knitting and designing Easter eggs. Diane is often reluctant to admit defeat from her disease, and she often attempts strenuous tasks without assistance and resists reliance on adaptive equipment. Diane is adamant that she must keep her body active in order to prevent further damage.

Diane's daughter Vicky is 36 years old and has High Functioning Autism. She is employed at a local grocery store one day a week, and spends the rest of the week at a

community centre that provides vocational skills development for adults with intellectual disabilities. Vicky is fairly independent and able to make her own breakfast, pack her lunch, feed the cats, wash the dishes, take out the garbage, and take the bus to work. Vicky's schedule allows her to know exactly what she will do at work and what she will do when she comes home. As long as this routine is secured, Vicky feels safe and content in her own environment.

James is 42 years old and suffers from several medical conditions including visual impairment, arthritis, psoriasis, and back problems. James is independently mobile, but he is unable to read or write because he is legally blind. James has been living with Diane and Vicky for 20 years, since he befriended Diane's daughter Emily in high school. When his parents had him leave their home, James moved in with Emily's family, which at the time included Diane, her husband and Vicky. When Diane and her husband divorced and Diane became ill, James remained in the home as

Diane's caregiver. Twenty years later, James continues to provide many aspects of Diane's personal care. He assists her with bathing and toileting, financial matters, medical appointments and regular household chores. James identifies himself as Diane's platonic friend and caregiver. James explains that he and Diane were friends before she became ill, and that they have supported each other through difficult times. Diane, Vicky, and James each support and care for one another.

As a team we try to do everything together and do the best we can, and go with the flow. (James)

In the morning, James helps Diane sit up on her bed and do her morning exercises. James helps Diane bathe, use the toilet, put on new incontinence pads, get dressed, and move into her powered wheelchair. Vicky usually wakes up by 8:00am and prepares herself for the day. She helps Diane brush her hair and then she makes breakfast for the trio before catching the bus for

her daily activities. Diane spends most of the day reading books, newspapers, and newsletters from the MS Society. James works from home and cares for Diane throughout the day. For example, when Diane needs to use the washroom, James helps her move onto the toilet and then goes back to work. When she is finished, Diane calls James again, and he helps her back on the wheelchair. James prepares lunch for himself and Diane and they often eat together. When Vicky arrives home in the afternoon, she usually has a short rest and then washes the dishes, cleans the house and cooks dinner. Vicky is allergic to lactose, and Diane takes great care to watch over meal preparations and ensure that Vicky's food is not mixed with cow products. After dinner, Vicky washes the dishes and James takes an evening nap. Vicky then cares for Diane by assisting her to change into her night wear, wash her face, and brush her teeth. Before midnight, James wakes up to help Diane move into the bathroom again and he changes her incontinence pads. James then helps Diane move into her bed, where she usually sleeps

for six hours.

Diane cares for Vicky in ways that are less visible than the tasks that Vicky and James perform for her, but the tasks nonetheless encompass a caregiving role. While in the past she provided hands-on care and considerable advocacy for her daughter, Diane is now limited in the physical care that she can provide, though she contributes as much as possible. For example, Diane assists Vicky with cooking by providing detailed instructions and monitoring as Vicky prepares meals. Vicky explains: "Yes, I usually make the meatloaf with mom when mom makes meatloaf." Diane is often the mind behind the recipes, as she coaches Vicky and provides detailed instructions to perform tasks that her disabilities prevent her from doing. Vicky also plays an important caring role in the home by doing the housework and assisting with meals. Diane cares for James by assisting him with his computer work and reading documents to him. James is grateful for the friendship and advice that he receives from



Diane.

James is generally comfortable providing care for Diane, but he wishes that he could meet all of her needs. He becomes disappointed when he cannot accomplish personal tasks for Diane.

You got to fight and pull her's teeth, to colour her hair even, for example. I can't see well enough to do it, so have to pick, and scratch, to get somebody to come in and colour her hair. And it's pretty sad when you can't get somebody to do that, I might be good to help out in many ways, but I have my limitations as much as I can do.

Diane, Vicky and James receive little external support in their caregiving roles, and they express frustration at feeling “stuck” in

their unusual arrangement.

There is nobody to fall back on, no caregiver assistance, there is none. You know you're pretty much stuck. You go regardless, you know you just hope and pray you don't get sick, and when you do get sick it's not that bad that you can still follow through.

James explains how burdensome the normal caregiving tasks can be when he falls ill and has no respite care.

When my arthritis is bad, or when I have a headache, and she needs to go to the bathroom. You know going to the bathroom the number of times she does in the run of the day, normally don't bother me but they tend to get to me

more, when I'm not feeling well. Or when she's sick, you know when she's sick it becomes more of a load. Not her fault, but I don't help matters at times. I'm not perfect but I try to do the best we can.

Diane, Vicky, and James do not receive any home care support. Diane used to access bathing services three times a week. However, Diane explains that these services were reduced, and replaced with occasional sponge bathing. Diane tried to negotiate the time of her bathing, as it would be better for her to get bathed in the mornings when she has more energy.

In the afternoon, later in the afternoon, I get weak. And I'm really worried about this strength. So I told her, I said, “Look. Try to make my appointments early. Give me a bath early, I have lots of strength.”

And they started doing it later, and later, and later in the day.

Over time, the home care service conducted an assessment of Diane's bathing service and concluded that a lift was necessary to continue the service. However, at a cost of \$1,000 the lift was not affordable to Diane and her family. In addition, Diane felt that the lift would restrict her ability to hold herself up and maintain use of her already limited physical functions. Diane now receives no home care services, and James only has time to bathe Diane once a week, as the procedure can take up to three hours.

Diane, Vicky, and James are each caregivers and care recipients to each other. They each experience tremendous stresses that results from their own disabilities, strains of caregiving, and a lack of financial support. Diane, Vicky, and James each receive disability pensions, and Diane maintains ownership of a small income property. Even when these incomes are combined, the family is unable to cover all

of their necessary experiences. In addition to the regular costs of living, Diane needs to pay for all her incontinence supplies and additional medical equipment. Financial restrictions have prevented Diane from enrolling Vicky in programs for people with autism, but she feels that Vicky is learning to be independent by caring for her mother.

Diane believes that Vicky will soon need to live independently, and she worries that if James were to leave there would be no one to care for her. Diane is dependant on James and requires his support to remain in her home. Although Diane has fears that James might move her into a nursing home, James appears to have no such plans. James believes that God will provide him with the strength to care for Diane well into the future.

I honestly can't see my life being better without her, but we've done so much together. Everything we do is together, and I hope and

pray that will continue for years to come.

As a mother, Diane also feels that caring for her daughter is natural and she finds reward in watching Vicky "learn to deal with life in general, one day at a time." Diane, Vicky, and James remains committed to caring for one another as long as they are able to do so.

Postscript

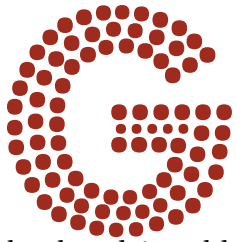
Following the research period, Diane, James, and Vicky decided to move to British Columbia. The trio boarded a bus from Halifax and endured a seven day trip to Vancouver, with a brief stay in Alberta when the bus that arrived to finish the final leg of their trip was not wheelchair accessible and they had a delay while waiting for a replacement. Ten days after they arrived in British Columbia, Diane passed away. As Diane anticipated, the two legs of the tripod no longer have balance after one has gone. Vicky and James now live separately and struggle to find new meaning in their lives.



Ghislaine's Portrait

"I could be doing probably better, I probably could enjoy my life better, but I know it's not his fault. I have to deal with it."





hislaine is a forty-eight year old Acadian woman who lives in a quiet village with her husband Arnold, their twenty-four year old daughter Andrea, and Andrea's two year-old daughter Ruth. Ghislaine was born in New Brunswick to a large French-speaking family, with eleven brothers and sisters. Arnold is a sixty-seven year old indigenous Black Nova Scotian, and one of more than twenty children. Ghislaine and Arnold met in Quebec nearly thirty years ago. Arnold could not speak French and Ghislaine spoke little English. Despite the language barriers, they began a relationship that developed into a strong marriage that has survived for more than twenty-five years.

Ghislaine is now a full-time caregiver to Arnold, whose health has declined over the years through a series of strokes of increasing severity. Ghislaine began caring full-time for Arnold ten years ago following his fifth and most severe stroke. This

stroke left Arnold with paralysis in his right arm and hand. The stroke also left Arnold unable to speak or write. Arnold can now communicate only by nodding or shaking his head in response to yes/no questions – occasionally responding opposite to what he actually means. Following Arnold's final stroke, he remained in the hospital for several weeks and then was transferred to the Rehabilitation Centre in Halifax for further treatment and therapy. When Arnold was released from the Rehabilitation Centre, their home was restructured to accommodate his wheelchair, with a wheelchair ramp leading up to the back door of the house, handrails on either side of the front hallway, and a hospital bed in his bedroom.

Ghislaine had a difficult time with her role as caregiver when Arnold first returned from the Rehabilitation Centre. She needed to adjust quickly to the new reality of their relationship, in which Arnold was no longer her independent and active husband, but rather a highly dependant man in need of physical and emotional care. Caring for Arnold

occupies most of Ghislaine's time, as she is either caring for Arnold, explaining caregiving tasks to home care workers, or buying groceries and doing housework. Even when Arnold goes to the bathroom, Ghislaine stands right behind him to ensure that he does not fall.

Well, the main thing is it's very difficult, and every day is the same. It's not just whenever you feel like it; every single day you have to do what you have to do. You have to take care of him every day.

Ghislaine's caregiving necessitates close attention to Arnold's behaviour and non-verbal communication. Caring for Arnold means ensuring that his physical needs are met, from brushing his teeth to helping him get dressed. Ghislaine's caregiving work also involves tending to Arnold's less visible needs, such cooking special meals or changing the television

channel to a program he enjoys watching. Ghislaine describes a typical day caring for Arnold:

Well, I usually get him up in the morning, I have to help him get out of the bed because we have a hospital bed and he can't get out by himself. And I just get him dressed and then I take him to the kitchen and then I make his breakfast, and then after that I have to give him his medication. And then we usually, well I take him to the bathroom and wash him up, and comb his hair, and brush his teeth, all that stuff, all the personal care. Then I take him back out, and then I usually do his exercise for his right hand because his hand's still paralysed. I have to do that every morning

because if I don't it will get stiff after a while. And then after that we just, we usually watch TV. We watch quite a bit of TV 'cause there's not really too much more he can do besides that, so when he watch TV that's when I usually do my housework. Then when I'm finished, then sometimes we go in town and do some errands or grocery shopping or whatever I need to do in town.

Arnold often accompanies Ghislaine on her errands, but he usually remains in the car while she goes into the stores.

[S]ometimes I'll only have a couple of things to get so, you know, so I find it's a lot easier just to go in, get my stuff and come right out. And he's okay

with that, because a long time ago I used to take him with me and one time his legs sort of gave up and I got scared and I, you know, I didn't know what to do. Then I was looking for a wheelchair in the store but it was hard for me to get to it because I have to hold on to him, so he won't fall because he looked like he was going to fall and so I got scared and that's why I don't want to do it any more now, because it makes me really nervous. I'm just not comfortable with it any more.

When Ghislaine became her husband's caregiver, she was not informed of her eligibility for respite services. When she eventually learned of her entitlement to relief work, she quickly learned how to arrange for two days of respite each week



from the Victorian Order of Nurses (VON). In addition to two days of respite per week, Ghislaine also received one evening of respite per month. She tries to use this time to see a movie or visit a flea market. Although Ghislaine is eligible for additional respite time in the evenings, she cannot afford to go out more than one evening per month.

Like at first I didn't really know about it, I mean, you know, sometimes it takes a while before you find out all the information. But then, you know, the home care worker was talking to me about it and I said that sounds like a good idea. Sure, I would love to have some time to myself! And I would probably even like to have even more than four hours a month, you know, that's not much, that's only one evening a month, you know, but

tell you the truth, I mean well maybe in our case it works out all right because it's just that you know it's only Arnold's income right? I don't have no money coming in at all so it's kind of hard for me to go out more than once a month anyway. But I mean I would like to but it's just I don't know, it costs money to go places and do things...

Ghislaine also learned about an adult day program from the VON, and after a two-month waiting period a space became available for her husband. Arnold now attends a hospital program two days per week, and a bus service is available to transport him to and from the local hospital. Although she would like to use this time for personal activities, Ghislaine spends most of her respite time running errands, doing housework

and caring for her granddaughter.

Throughout the many years of her husband's illness, Ghislaine had many interactions with health care professionals, and their geographical location in a rural Nova Scotian community has served most of their needs. Ghislaine and Arnold live ten minutes from a major hospital, and twenty-five minutes from a smaller hospital where Arnold attends the adult day program. When Arnold was recovering from his most recent stroke at the Rehabilitation Centre, the distance from Halifax meant that Ghislaine could not visit Arnold every day. This is the experience of many rural people whose local hospital is adequate for ordinary illness, but does not provide specialized care for severe illnesses and disabilities.

Following Arnold's fifth stroke, their frequent visits with the hospital and rehabilitation staff were quite positive. Ghislaine's regular interactions with the health care system are now limited to Arnold's home care and the adult day program at the local hospital. Ghislaine has been

pleased with the care provided by most home care staff, but she expresses discontentment over their frequent rotation.

We have a whole list of people, oh my goodness. [...] I don't like this idea and Arnold doesn't like it neither because every time we have a new one then we have to explain the whole thing all over again...Like I always ask them: "Do you know anything about Arnold, did they tell you anything about him?" And they say: "No. They just send us over here and we just take it from here." . . . They don't know what to do.

Ghislaine has created an information package for home care workers unfamiliar with Arnold's care, but she feels that the staff rarely has time to review the material. Despite her efforts

to prepare written instructions for new home care workers, Ghislaine usually finds herself using her own respite time to explain Arnold's routine.

Ghislaine experiences ambivalence over her role as a caregiver. While she feels that it is the right thing to do for Arnold, she finds it difficult to be his primary caregiver.

Well I feel like I don't have any choice, but to go on with it...Well I feel like, if I – I don't know how to say it. I know if I take good care of him, I make him feel better and it makes me feel better too. Because I know that he needs somebody, and you know I'm sure if I let him down he wouldn't feel too good about it...I'm sure he would do the same thing for me, you know if the same were to happen to me before it happened

to him, I know he would have done the same thing for me. I know that for sure... I find that hard, that I have to be home all the time. I could be doing probably better, I probably could enjoy my life better, but I know it's not his fault. I have to deal with it.

The only financial support that Ghislaine and Arnold receive is from Arnold's Canada Pension. In addition, since Arnold is over the age of sixty-five, he and Ghislaine no longer have a drug plan to cover the high costs of medication. Ghislaine believes that she and Arnold would enjoy a higher standard of living if she were provided with an income for her full-time work as a caregiver. Ghislaine believes that there should be an income or pension provided to caregivers.

I think they should come up with something, you



know like for caregiver to have some kind of income coming every month. It's very difficult when you have to stay home. I don't have any income coming in at all, and I have to look after Arnold.

Poverty and illness have combined forces to isolate Ghislaine and Arnold from their families. Ghislaine's family lives outside of Nova Scotia, and she has not seen them in many years. Arnold is unable to make the long drive, and they cannot afford airfare or long-term home care for Arnold. Not only has Ghislaine lost her connection to her family, but she has also become disconnected from her Acadian culture. Ghislaine also feels that her relationship with her children has also changed, in that she has become a single parent.

He cannot really help me out right now, like I have to do all the talking with them and trying to do the right thing. It's hard

because sometimes I don't always know what to tell them. I mean it would make it so much easier when you're a couple, you know.

The greatest and perhaps most devastating impact of caregiving has been on the relationship between Ghislaine and Arnold, fuelled by perpetual silence.

Well it seems like we felt closer before, because before he could show me love. But now he cannot show me, I mean I don't have that feeling anymore. I don't, he can't really show me.

If Arnold's condition remains stable, Ghislaine intends to remain in her role as his primary caregiver for years ahead, with the awareness that they will continue to experience financial and emotional strain. Nonetheless, Ghislaine relies on prayer to sustain


her and she remains committed to caring for her husband for as long as she is able.

I do get depressed lots of time, but I say to myself what can I do to change the situation? There's not really, it doesn't matter how depressed you get you still can't change the fact, you still cannot change what's happening. You can be depressed as much as you want it won't make no difference. It only going to make it worse, so I have to think that way...And I have to think about maybe it might be some better days ahead, you know. I'm hoping anyway. I guess it's good to have hope.

Julia's Portrait

You'll disappoint yourself in this role and you'll surprise yourself in this role, at the strength that you have sometimes.





Julia is a fifty-eight year old Caucasian woman who lives in a small rural town an hour from Halifax where she and her partner Michael are the primary caregivers for Michael's ninety-year old mother Charlotte. Julia and Michael have lived together in a common-law relationship for over thirty years. They retired six years ago and bought their current home, which is bright, comfortable and immaculate with a cozy lived-in feeling. Prior to becoming Charlotte's caregivers they enjoyed outdoor activities such as hiking, cross-country skiing, biking and camping. Soon after their retirement, Michael's father had a stroke and moved into a nursing home, dying shortly after. When it became apparent that Charlotte was quite frail and unable to live independently, Michael and Julia immediately moved Charlotte into their home. Michael's parents had been married for fifty years in an abusive relationship, and Michael and Julia hoped to provide Charlotte with the life they felt she deserved. However, not long after she moved in with Julia and

Michael, Charlotte was diagnosed with cancer of the bowel. Surgery to remove a large tumour was successful, but it required Charlotte to have a colostomy, and led Julia and Michael to become her full-time caregivers. Their home has since been designed to accommodate Charlotte's needs, particularly the bathroom which has a safety frame attached to the toilet and grab bars on the wall. The bathtub always holds boxes of latex gloves and there is always a row of toilet paper squares lined up next to the sink to clean Charlotte's colostomy bag.

Once Julia and Michael invited Charlotte to live with them, all of their time became focused on her care. Charlotte is able to walk with the assistance of a cane, but she requires assistance with eating, bathing and getting dressed. Julia and Michael work as a team in caring for Charlotte, although Michael is quick to credit Julia as Charlotte's primary caregiver because she helps Charlotte with her personal care, including bathing, dressing and setting her

hair.

I help her bathe, then I help her dry off, and then I usually massage her with cream at least once a week. I wash her hair and I put her hair in rollers, and set it. She has to have supervision to dress, and make sure all her clothes are clean and I do most of the laundry and just get her ready for the day...So by the time we get her dressed and ready for the day then it's breakfast. She has to have her medication in the morning, which we look after; she just would be too confused about it. So then that's breakfast, then after that we get Charlotte settled for the day and she usually just comes in and goes to her chair, and we

usually have to remind her to brush her teeth because she wouldn't even think about that. She would just go and sit, she just loves to sit... Anyway we say to her, "Now don't you think you should be walking a little before you settle in for the day?" and so then we make sure she walks around the house. ... Anyway she settles down for the day and then I go on with my chores, which would be laundry, cleaning, cooking, whatever you do with the every day chores. (Julia)

In providing 24-hour care for Charlotte, Julia and Michael have sacrificed their own health and relationship. A large part of the care that Julia and Michael provide is emptying and cleaning Charlotte's colostomy bag, which needs to be emptied every few hours. There is an intercom system

in the house, and Charlotte calls for help throughout the day and night, which renders Julia and Michael in a constant state of sleep deprivation.

So we've aged terribly . . . I wonder if we can rejuvenate ourselves. Maybe not appearance-wise, but health wise we're hoping. Julia didn't realize that she had osteoporosis. . . I think this chronic fatigue is just depleting our own resources. (Michael)

In the years that they have cared for Charlotte, Julia and Michael have had very little time alone together, with the few hours a week of respite care occupied by mundane tasks like shopping for groceries or paying bills.

That's a concern of mine. That Michael's and my relationship, I find that this is one of the reasons,

with the sleep deprivation we are having words with each other, and sometimes I think that when this is all over if we continue to look after his Mum the way we've been doing, we may not have a relationship. And that really worries me and makes me anxious . . . I am going my separate way, he's doing his own thing and I said when she is not with us anymore, okay we're going to look at each other and say look, okay do we know each other? Because I am doing things on my own. So that worries me, that our relationship, you know, has not been as close, we haven't have time for each other, and it concerns me that if we keep going down this road, there might not be a



relationship to salvage.

In the months leading up to their decision to place Charlotte in a nursing home, Julia and Michael began to recognize the signs of reaching the burnout point in their ability to provide appropriate care.

We realize what the burnout signs are, and well, if you burn out well then, she would end up on an institution anyway. So you can recognize those signs early and do something about them, not necessarily meaning put her in a nursing home, but somehow get more help...We were told of what stress, and this type of sleep deprivation can do for you. I said these are symptoms and we are being given some warning. Let's heed the warnings,

because it could happen.

Through several interviews and observations during this research period it became evident that Julia's most significant caregiving contribution lies in her small gestures of intimacy and love. For Julia, caring for Charlotte means cleaning her glasses, matching her clothes and warming her hands, all of which exemplify constant efforts to read her body language and anticipate her needs. Yet Julia's actions are neither anxious nor frantic: it is a seamless motion, tending to her mother-in-law's needs as if she were brushing her own hair out of her eyes. An action completed a thousand times, done without conscious thought, yet with precision.

Our ears are just tuned in to her so much that it's just like people who have babies. They can almost tell when the baby is awake and when the baby is asleep even without being there, you know they

just have this instinct.

This caregiving is almost invisible yet it comprises most of Julia's time and thoughts as she strives to make Charlotte feel happy and fulfilled. Julia and Michael express frustration with Julia's reluctance to tell them how she feels and what she needs.

Lots of time she won't respond to us. I will ask her a question, I'll just ask her, you know if her hands are cold, or whatever and she'll just look at me, she won't say yes or no, because if she says yes she knows what my immediate reaction would be, is to go out and to heat up her oat bags to bring in to her. To her, that's a bother to me, even though it takes maybe a minute and a half, and I'll tell her that. I'll say, "Charlotte, please remind

me to do that because I don't mind doing it at all." (Julia)

Julia's feelings about being a caregiver are generally positive, particularly when she and Michael put Charlotte to bed at night and she thanks them for all they have done for her. However, the nature of full-time caregiving has created frustration and exhaustion for Julia and Michael, and it was these emotions that led the couple to need to place Charlotte in a nursing home after five years of caring for her.

Well you know, I don't regret it for one minute. But there are times when I feel I am just going through the motions, because I am so tired and that makes me feel guilty, because I am not doing the care with love, you might say. I am just going through the motions saying well here's a person who needs this

and needs that...I just, it's just do what I have to do and then of course I have guilt feelings for that. Then I think: "Oh my goodness, I hope she doesn't notice." And of course I would never know if she noticed or not, I notice it. And I would not want to get to the point where I might even get belligerent.

Julia and Michael have been involved with many aspects of the medical system since Charlotte moved in with them. They voice frustration over the lack of information provided to them in terms of support they could receive in caring for Charlotte. In the first two years of caring for Charlotte, Julia and Michael did all of the work themselves with little respite. They eventually learned of an adult day program which allowed them about five hours to themselves one day a week. However, they often found that they were so tired from having been awakened constantly

in the night that they would use the respite time to sleep rather than run errands or spend time together. A year later, Julia and Michael learned that they were eligible for respite from the provincial government's Home Care Program. They withdrew Charlotte from the adult day program and instead had respite workers come to their home two days per week. The respite workers spent time with Charlotte and gave her lunch that Julia prepared in advance. Even with respite care, Julia and Michael felt their time was spent caring for Charlotte.

We found out about home care, and we've getting that and it's been the greatest, from the Home Care Program. . . But it's very seldom we are not doing things like shopping for groceries, getting prescriptions, things like that and we could get a little walk in somewhere or another. Everything is



closed, nothing is opened, we couldn't stay a little longer; we were so conscious of watching the time.

After five years Julia and Michael agreed that they could no longer function as Charlotte's primary caregivers and they arranged for Charlotte to be placed on the waiting list for a nearby nursing home. Placing Charlotte in a nursing home was a lengthy process involving numerous steps; most of this work was done with the help of the Head of Continuing Care, who came to their home to assess Charlotte's needs. Throughout this whole process, they found all the health care professionals with whom they had contact extremely supportive. As they waited for a bed to become available, they continued to care for Charlotte as they had for the past five years. After more than five months, a bed became available in the facility that was their first and only choice for Charlotte. Julia and Michael continue to provide care to Charlotte now that she has entered the nursing home,

although Julia says "we aren't 100% her caregivers now." When she visits Charlotte in the nursing home Julia continues to do many of the same caregiving tasks that she has always done: setting Charlotte's hair, cleaning her colostomy bag, and checking her medications.

Julia feels that the healthcare system is overworked and understaffed, and that hospital staff are too busy to give the same level of care that Julia and Michael had provided. Her suggestions for improving the health care system involve hiring more staff to cope with the ever-increasing aging population. She would also like to see more education for caregivers on issues of medication management, lifting techniques, stress management. Julia and Michael only learned about many of these issues by attending a workshop organized by the Nova Scotia Caregivers Association, after five years of coping on their own.

Julia and Michael feel that their rural location contributed to their relatively positive experience

of caring for Charlotte. They never had to drive to Halifax to access health care services, as all necessary services were close to their home, including the family doctor across the street. Julia is pleased to live in "an advantageous county" with shorter waiting times than in the city. When homecare workers came to their home there were only three different workers whereas in urban settings care recipients often see the same worker only every few weeks.

Although Julia and Michael are no longer Charlotte's primary caregivers, they continue to be involved in her life and her care. They continue to talk to the staff about the care that Charlotte receives and ensure that she received the best care possible.

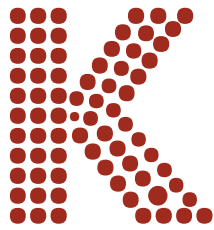
Postscript

Two months following the completion of the research, Charlotte became gravely ill and passed away. Julia feels that palliative care for Charlotte was made easier in the nursing home, although Michael continues to feel ambivalent about their decision to place his mother in long-term care.

Karla's Portrait

I've often said, at the end of the day there are days when I haven't had a chance to be a parent.





Karla is a 27 year old Caucasian woman who has lived in the Halifax Regional Municipality for her entire life. She is a single parent and the primary caregiver to her seven-year old son Anthony who requires 24-hour care. In addition to her caregiving responsibilities, Karla is enrolled in part-time studies at a local university. Anthony is a warm child with big brown eyes and short dark hair. Anthony was born with multiple disabilities under the umbrella term of Cerebral Palsy, and Karla has been his full-time caregiver since she brought him home from hospital, two months after delivery. Anthony's condition has affected his physical and intellectual development, and he has difficulty with verbal expression, vision and hearing. Anthony uses a wheelchair for mobility and requires assistance to maneuver the equipment. Despite these significant limitations, Anthony is an engaging child, aware of his surroundings. Anthony attends a primary public school where he is very well liked by classmates who

include him in play-dates and birthday parties. One of Anthony's closet friends is eleven-year old Emma who has lived with Karla and Anthony since she was a baby. Emma provides considerable assistance in Anthony's care, and helps by wheeling him to school, feeding him, and lifting him from his wheelchair.

Karla, Anthony and Emma live in a housing co-op in the Halifax area. The home is well-suited to their needs. It is spacious and wheelchair accessible with ramps and an elevator that connects the two floors of the home. As Anthony's primary caregiver, Karla is involved in every aspect of his care.

When you care for somebody who is total care, it's like taking care of two of you. So if you can stop to [think] for a moment how you go about getting yourself out the door everyday, literally right, you don't just get

out of your bed and leave. The whole procedure, and all of how you would take care of yourself personally, and every little detail from your uni-brow to your fingernails to your belly button fluff, it's basically [that] times two... The same things that I do to keep myself clean and all that, I just do the exact same thing for him.

Every day Karla changes Anthony's diapers, dresses him, feeds him, and gets his books ready for school. The upstairs bathroom is equipped with a lift and harness that Karla uses to bathe Anthony every second day. Three times a day Karla prepares Anthony's food and feeds him through a tube that goes directly into his stomach. At mealtime Karla wheels Anthony into the kitchen, adjusts his chair and lifts up his shirt to the spot where the feeding tube enters his stomach and carefully slides a towel under the tube hole. She then inserts a

long, narrow plastic tube into the opening of the feeding tube that leads into Anthony's stomach. She proceeds to fill a syringe with the fresh liquid mixture, and empties the syringe into the tube. Every night she hooks Anthony up to a pump that provides him with water. When Anthony becomes ill, the amount of care he requires increases significantly. Several times a year Anthony will have respiratory illnesses and he often requires 24 hour care. To avoid trips to the hospital, Karla has equipped her home with aerosol masks, oxygen, and suction machines.

Karla is very affectionate toward Anthony and in tune with his every need. She looks into his eyes or watches his facial expressions to determine how he feels and what he needs. An incredible part of witnessing Karla interact with her son is the realization that her caregiving tasks are interwoven in a loving mother-son relationship: Karla and Anthony have time together that does not centre on physical caregiving tasks, but rather moments of playfulness or affectionate bonding. For example,


when Karla sits on the couch to relax, she will lift Anthony up and hold him while rocking him back and forth. It is important to Karla that she treats Anthony with the dignity and respect that he deserves as her son.

In addition to caring for all of Anthony's physical needs, an important part of caregiving for Karla is making sure that Anthony develops relationships with other people. Karla has used a variety of strategies and techniques to help ensure that he forms friendships at school. Karla considers inclusion to be of paramount importance to Anthony's quality of life, and does not enroll him in activities that would segregate him from able-bodied peers.

When Karla voices frustrations and complaints about her role as a caregiver, she speaks not of physical caregiving task but rather of experiences with the health care system. Karla spoke at length about how the overall system has consistently failed to meet her needs as a caregiver, and how she believes the system needs to change significantly

in order to address the needs of people with disabilities. Karla's greatest challenges in her role as a caregiver have involved his care at the local children's hospital. Karla has grave concerns about Anthony's treatment at this institution, and she has worked extensively to advocate for her son to receive adequate hospital care. Her concern for his well-being when admitted to the hospital has been so great that she found it necessary to place a "Please Resuscitate" form in the front of Anthony's file, as she felt that the staff would leave her son to die if his condition became critical.

I always, well, at least regularly, walk into him being devalued as a human being over there. I think that the practice of eugenics is massive and huge over there...I think that it's a huge threat to me and other families in my situation, and to be honest, that is what I fight against over there.



I fight for his value. I'm basically faced with their attitude of "he'd probably be better off if he'd passed away." They've asked me many times what kind of treatment did I want, even for things like pneumonia. So basically at any point I could choose to let him die over there, no questions asked. ... The next time he got sick he'd pass away and it would be that simple. In fact if I were to bring it up, it would probably be encouraged.

When Anthony is admitted to the hospital, Karla remains at the hospital around the clock to supervise all of Anthony's care and ensure that he receives his medication on time and in the proper way. Her concern for Anthony's well-being in the hospital was heightened after she discovered his nurse was preparing to give him Children's Tylenol, a medication that causes

Anthony to have seizures. Since Karla has become more assertive about her expectations of how the hospital staff should treat her son, she feels that the care has been slightly more attentive.

So she knows I'm not fooling anymore... And I've made it clear to her that she is to treat my son as though he were her own. And I would expect not one little tiny bit less.

Karla has accumulated medical supplies and technologies in her home to minimize Anthony's hospital admissions as much as possible. Karla also feels burdened by her role as a caregiver to Anthony when high-risk medical procedures are proposed because the burden of assessing the risks and making a decision falls to her.

Sometimes, it's easy to say to yourself, "Why am I left with this kind of decision?" I don't want

this kind – I don't want to have to make these kinds of life decisions for another human being. Why am I put in this position? Why do I have to hold this bag? I joked with another parent about it recently, and said, "I've been asked a lot of times, what are the shitty things about caregiving? And I've always been quick to say, well there aren't any." And I was kind of joking with her, and I said, "Except for this! This is shitty!! (laughs) This would be one of the really shitty things!"

Karla's mother is a homecare worker by profession, and when Karla went back to school she arranged for her mother to become Anthony's homecare worker. Despite being able to benefit from her mother's employment, Karla remains unsatisfied with

the amount of homecare that she receives and Karla believes that all caregivers and individuals with disabilities should have access to 24-hour support.

Right now I don't even need 24 hour care, but I can't even get what I would need. If I could live in a perfect world I would have somebody... and again there might be many days where I would call a person and say, "I'm not in need of support today." But I at least want the option so that there'd be somebody here from the time he got home from school to the time he went to bed, everyday. And that I'd also have the option of having every single weekend to myself if I want it that way. [That] is really what I would love to

be able to have right now.

As Anthony's full-time caregiver, Karla's financial needs necessitate on-going contact with a number of social services including In-Home Support, Employment Support and Family Benefits. In addition, Karla received monthly payments from Employment Support & Income Assistance (ESIA). She has encountered numerous conflicts with her Employment Support worker around the issue of attending University. ESIA policy will only pay for two years at a community college, but Karla feels that a college education alone will not lead to employment that will allow her to become financially independent, particularly given the extraordinary expense of caring for Anthony. Karla presents a critique of the ways in which this system has made it very difficult for her to gain financial independence. Karla plans to continue fighting to secure funding for university, and if social services are unable to provide the support she requires, she will take her concerns to the government.

Karla also voices frustration about

the lack of information provided to her about the services and funding that she was entitled to for Anthony's care, and the lack of support she received to prepare proposals for funding.

[O]ften times, if you show on paper that you need it, you'll get some more support. But you've got to know stuff, and so I had to go and educate myself first before I could even attempt- because it's a proposal, you need to literally put in a proposal with a budget and everything, to get it.

This research and proposal writing takes a lot of time and compromises her time with Anthony. Karla benefits from an informal, personal network of parents of children with disabilities and adults with disabilities to whom she can turn for information and support. These informal resource networks are critical to Karla's self-education in regards to her



son's care, however, she asserts that formal support and resource services must be available to caregivers.

Caregiving has had a significant impact on Karla's priorities and goals, and she is committed to working toward validation for individuals with disabilities and their caregivers through her involvement with several advocacy organizations. Karla draws a firm distinction between caregiving and parenting.

To fellow parents, I would say, "Caregiving is not your job. It's not part of parenting. It has nothing to do with being a parent." We ought to be paid, as parents, dollar on the hour...Sure, all parents do some caregiving, that's not what I'm saying. But what I do, and what other parents in my situation do, is not parenting. We do somebody else's

job. Somebody else's job who normally gets paid. So, every bath we give, every ass we change, every meal we feed, every physio session and OT session and splints we put on and augmentative communication and all of those programs and real physical hands-on stuff, that isn't parenting. I've often said, at the end of the day, there are days when I haven't had a chance to be a parent.

Karla believes that her location in an urban centre has greatly facilitated her role as a caregiver.

Given the high level of care and medical intervention that Anthony requires, it would be very difficult for Karla to care for him if they lived outside the city. While many of his appointments with health care professionals are planned, if Anthony experiences respiratory problems his need for

medical intervention can become quite urgent. Living in the Halifax area enables Karla to have greater access to support networks and has facilitated her involvement with urban community advocacy groups. In addition, living in the Halifax area has positioned Karla nearby several universities and enabled her to return to school.

Karla will continue to care for Anthony at home, and advocate for changes to the system. Karla is adamant that she will never place Anthony in institutional care, and takes issue with the fact that the government will pay for institutional care and not caregivers. Anthony has brought joy and meaning to her life:

You have to arm yourself with information. And I think that before parents can even take that step to go and look for the information, they need to really look at their child as the huge, huge gift that they are. And I've always

found some peace in the fact that people who meet my son are different. They come away different, better people. And I think that if society never had a reason to be grateful, what a society we would have. So in a lot of ways I think that my son is the catalyst for true happiness. And without him I don't think it can exist.



Leanne's Portrait

"I would ... not stand by and see her go into a hospital or nursing home."





Leanne is a single African Nova Scotian woman with a bright smile and dark, laughing eyes, the eldest of eight children born and raised in Halifax. Leanne has lived in an attached, two-level subsidized dwelling for over twenty years, raised a son and a daughter, and is now a successful entrepreneur with a home-based business. Leanne is the primary caregiver to Mrs. Kay, her ex-mother-in-law, with whom she had been estranged for over a year prior to embarking on their caregiving relationship. Mrs. Kay is a soft-spoken 75-year old with numerous health conditions. She is hard of hearing and suffers from visual impairments, including cataract. Mrs. Kay has diabetes, a condition which led to kidney failure and now necessitates kidney dialysis to maintain her health. By prior arrangement with the Victoria Order of Nurses (VON), a nurse comes weekly to prepare insulin shots for Mrs. Kay so that Mrs. Kay can give herself injections.

In addition to caring for Mrs. Kay, Leanne also cares for her own

mother. Leanne takes her mother to medical appointments, picks up her groceries, pays her bills, help with her housework and spends the night with her during difficult times. Although Leanne's mother does not live with her, her caregiving responsibilities are substantial. Leanne had been looking forward to living alone when her children moved out of the family home, but shortly before her daughter left, Mrs. Kay moved in with Leanne.

I was looking forward to my daughter moving out and my just being alone. I said after twenty-eight years, I said: "Oh, I'm finally going to be alone." Then all of a sudden [pause] bing!

The circumstances which led Leanne to become the primary caregiver to Mrs. Kay were not unusual. In the Fall of 2003, Mrs. Kay experienced a kidney failure and was rushed from her rural Nova Scotian community to a hospital in Halifax. With no

reliable relatives in the area, Mrs. Kay's sister asked Leanne to visit Mrs. Kay at the hospital, even though Leanne and her mother-in-law were not on speaking terms at the time. Once Leanne arrived at the hospital, the doctor relayed the seriousness of Mrs. Kay's illness, and that she would require full-time care in close proximity to the hospital.

So we went in and he told her... "You have to relocate," and she started crying. And she said "Can I come live with you?" And I said yes. Even though that wasn't what I was prepared for and I didn't think that's what was going to happen, [considering that] at that time we weren't even speaking. . . I think she asked me because deep down, she knew I would say yes and not stand by and see her go into a

hospital or nursing home.

Leanne is firm with her personal limitations in her role as a caregiver. She spends a significant part of her day preparing special food for Mrs. Kay, who has strict dietary requirements and cannot cook for herself. While Leanne finds great pleasure in trying new recipes and cooking for her family, upon Mrs. Kay's arrival she found herself cooking several times a day. Mrs. Kay is able to go up and down stairs on her own and she can sponge bathe herself, but she requires Leanne's assistance to get in and out of the tub. This is an extremely strenuous procedure for which Leanne has no special equipment. In caring for Mrs. Kay, Leanne helps Mrs. Kay maintain her independence as much as possible by encouraging her to fold her clothes, clean her bedroom and make her bed each morning.

In addition to providing physical care, Leanne is also responsible for managing Mrs. Kay's finances and scheduling health care appointments. Leanne usually escorts Mrs. Kay by taxi to her family physician every six

weeks and to a specialist when necessary. In relation to Mrs. Kay's care, Leanne has had positive experiences with the health care system, particularly in terms of accessing information from hospital staff about medical procedures and subsequent home care. Leanne found hospital staff to be particularly helpful when Mrs. Kay was sent home following surgery and became terribly frightened. Leanne called the hospital and the staff coached her over the phone to check Mrs. Kay's blood sugar, help her take her insulin and advised Leanne about what signs to watch for that would indicate a need to return to hospital.

When Mrs. Kay falls ill or undergoes surgery, Leanne's caregiving tasks increase significantly. For example, Mrs. Kay had surgery to insert a shunt in her arm, and throughout the long recovery process she was unable to use her arm. Leanne's regular caring tasks were matched with several additional tasks, from cutting up Mrs. Kay's food, to assisting her with dressing.

One area of frustration for Leanne

relates to transportation services to and from the hospital for Mrs. Kay's medical appointments. Leanne initially traveled to the hospital by taxi with Mrs. Kay, but this became too costly when the appointments were scheduled three times a week. Leanne was eventually able to obtain travel support through Access-A-Bus, a service that would pick Mrs. Kay up at her home, but there was no room to transport her home from the hospital. After another lengthy waiting period, space became available on the bus in both directions, but it usually leaves the hospital at set times that do not correspond with Mrs. Kay's appointment times.

Leanne expresses frustration at the lack of information for caregivers, particularly in terms of services that are available and how to obtain funding for such services. For example, she says that some people have transportation to and from hospital appointments paid for while others do not.

No, I don't [get any assistance for



transportation costs] and you know that's one thing that I don't understand. I called Veteran's Affairs, like because other people have been telling me that, you know when their parents were sick or something like that, you know they got help from Veteran's Affairs. But when I called them the women said, well no she's not eligible. I don't know, they don't give you any, there's no guide lines that I had, to tell me what's eligible and what's not eligible with Veteran's Affairs.

In general, Leanne struggles with not knowing what services are available to help her care for Mrs. Kay.

I think there are things out there that she may be

able to get, or might not have to pay out of her own money, but I'm really not sure. . . Just, you don't know what's available.

When Leanne agreed to care for Mrs. Kay, she received little support from her family. Her children were upset that she would take responsibility for a woman with whom she has been estranged for several years, and her siblings anticipated that she would have less time to devote to their own mother. Leanne's siblings felt that her role as a single woman with a home business rendered her the obvious family caregiver. Rather than expressing support for Leanne, and offering to help by providing more assistance to their mother, her siblings gave her a hard time about diverting her attention towards her ex-husband's mother.

One of the most difficult aspects of being responsible for Mrs. Kay's health and well-being is that Leanne has very little time

for herself.

You know, like extras. Like, I couldn't fit my exercise in. And that was bothering me. . . That was stressing me out a little bit, not being able to do that. You know, it's something I like to do.

Leanne aims to prioritize exercise as part of her daily schedule. The maintenance of a walking routine allows Leanne to support her own physical health, but also provides personal time to maintain her emotional stability. She also aims to socialize with friends outside the house every few weeks, and is grateful that Mrs. Kay supports her routine.

She knows what nights I am getting ready to go, 'Yes go,' she says, 'I'll be okay. You got to have some fun.'

Leanne feels that being the eldest

female child in her large family has carried a high degree of expectation and leadership responsibilities. Even though Leanne had taken on full time responsibility of caring for her children's grandmother, Leanne's siblings have not offered to increase the care they provide to their own mother. Leanne continues to be the primary caregiver to both her own mother and Mrs. Kay. Leanne explains that in her Black community is it expected that the eldest daughter will care for her mother. Since Mrs. Kay does not have any daughters and does not have a supportive relationship with her son, Leanne was assumed to be the most appropriate person to care for Mrs. Kay as well as her own mother. Leanne explains that extended family members in need of care are typically natural fixtures in African Nova Scotian homes, and the caregiving role tends to be undertaken by women.

[E]specially Black women.

A lot of us, well I wasn't but I know a lot of people were raised with their

grandmothers living in their homes and stuff like that. I mean, mine were both dead by the time I was born but you know that seemed to be a customary thing in the Black family... I think we've always done it [caregiving], but didn't put a label to it, like, you know, like I was going out doing things for my mother – that was sort of on a part-time basis – caregiving to my mother. But, any time we have our in-laws or an older member of the family living with us, we were always looking after them. And I think that's something that we just did! I would say it's part of our lifestyle.

Although caring for family members appears to have been a common occurrence in Leanne's experience, she believes that

caregivers should receive financial compensation and validation for their work.

[I]t's a job and [politicians and policy makers] should start looking at it as a job, and paying the people that are doing it a reasonable salary.

Leanne argues that she provides good care to Mrs. Kay, and that her work saves the government money that would otherwise be spent on a nursing home facility.

Well to me I'm giving my mother-in-law, I'll say better care than she would get in a nursing home because it's just one on one. Undivided attention. And it is a job, and I mean they can put them in a nursing home and take all this money from them, then why can't they pay the people that



are keeping them in their home, the same amount of money?

kinds of things. I am not a nurse.

Despite her long family tradition of caring for family members, Leanne feels that her own children would be unable to care for her if she became ill, and that she would be placed in a nursing home. She feels that older people themselves in the Black community are increasingly likely to feel comfortable with the idea of a nursing home, and that the modern reality is that adult women are often employed full-time outside the home and unavailable for family caregiving.

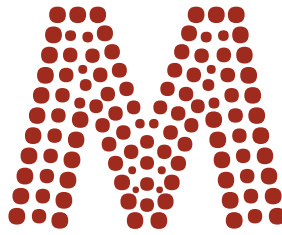
Leanne will continue to care for Mrs. Kay until she is in need of care that Leanne cannot provide.

When I guess when it comes to the point where she can't, I don't know, she can't use the washroom by herself and things like that. When she needs somebody to put her on the bedpan and these

Maggie's Portrait

"At that point, ... I shouldn't have been looking after anybody except myself."





Maggie is a fifty year old single Caucasian woman who self-identifies as a lesbian with several disabilities and health concerns. Maggie suffers from fibromyalgia, rheumatoid arthritis, environmental sensitivities, chronic fatigue and diabetes. A few years ago, these physical conditions were intensified by depression and suicidal feelings which lasted close to a year. In addition to managing these personal health problems, Maggie is a primary caregiver for her mother Mildred, an eighty-year old Caucasian woman with a soft, gentle face and sparkling eyes. Mildred has arthritis in both knees and was diagnosed with Alzheimer's several years ago. Mildred currently lives in the dementia wing of a residential care facility in Halifax, where she has her own large, bright room. Her room has been adorned with paintings and photographs of her grandchildren, and a collection of stuffed animals and dolls that she refers to as her "babies." Despite

her lack of awareness of her surroundings, Mildred is able to identify family members who visit her often, and she has retained her sense of humour.

Maggie recently graduated from university with a professional degree and maintains an active social life with a wide circle of friends. Maggie and her cat live together in a two bedroom apartment centrally located in Metro. Maggie is the youngest of three children born in Nova Scotia. Her father died when she was a teenager, and Maggie has always had a rather contentious relationship with her mother, fuelled by what Maggie describes as Mildred's extremely critical personality. Maggie began caring for her mother following the death of Mildred's second husband, when it became clear that her mother's abilities were diminishing.

[O]ne of the first things I had to do was start taking her for groceries. She stopped driving her car,

she was nervous of driving her car. Then my car broke down and she told me to take her car and use it, with the deal that I would take her for groceries and stuff. So that's what we did, and I'm still kicking and screaming about it... At the end of the month when her cheque would come in, I would take her shopping for her groceries and stuff. I'd drop in about once a week, once every two weeks to see her and to see if she's okay and I took her anywhere she needed to go. Then things started to happen...[one time] I had walked in and she had just finished cutting up a chicken or something, and there was chicken juice all over the counter. I said: "You know you have chicken juice

all over the counter.” She said: “I cleaned up.” It was all over the counter drying up. It freaked me out, because I thought: “Oh this is bad!” If she got sick, she’d die, at her age. She was in her 70s then, or no she was in her 80s. So I cleaned that up and I was telling my brother and sister about it, and we were all getting concerned.

Although Mildred now lives in a facility that provides all of her physical care, prior to this arrangement there were times that Maggie was responsible for all of Mildred’s physical care. For example, Maggie lived with Mildred for three months while Mildred was recovering from a total knee replacement. During that time, Mildred completely.

I had to bathe her, had to cook all the meals, had

to do her laundry, yeah, I was doing it all, basically. I didn’t have to change any dressings cause she didn’t have any but basically I was doing all that and getting her back and forth to physio...


Although this arrangement lasted only a few months, it came at a very difficult time for Maggie.

At that point, I was in the shape that I shouldn’t have been looking after anybody except myself ‘cause I was depressed then and I had just gone off work. So I was still really sick and I shouldn’t have been doing what I was doing. But there was nobody else to do it, right? So the reality is that people get discharged into the care of people who shouldn’t be looking after

them.

As a woman with several physical and psychological conditions of her own, Maggie’s experience of caring for Mildred has been wrought with challenges and frustrations. Maggie initially felt resentful of Mildred’s dependence on her and often refers to herself as being “enmeshed” with her mother’s needs. However, Maggie points out that her negativity likely stems from the fact that she was unwell and struggled to do full-time caregiving work when her mother first needed her help. This tension further challenged the caregiving arrangements, although in recent years Maggie has learned to give less weight to her mother’s critical personality.

I started realizing you know this woman isn’t going to change at this point, and she is always going to say: “Maggie you look fat in that.” She is always going to criticize what I do, and if I don’t



accept that then we're never going to have a relationship. So I think it took me accepting her, and not struggling with the fact that she wasn't the mother that I really needed, you know what I mean? So I had to just accept that, and then I started enjoying the little old lady that she is.

This negotiation of past differences exemplifies one aspect of the emotional complexity of the caregiving situation. Maggie seems to have generally set aside the pain and hurt her mother has caused her in the past in order to care for someone she now sees as a “neat little old lady.” Yet her mother still has the power to trigger old hurts with precision, which makes it exceedingly difficult for Maggie to remain caring and generous towards her mother.

Over the many years that Maggie has been a caregiver to Mildred, she has interacted with many

different aspects of the health care system. One difficult aspect relates to the lengthy waiting time for services and institutional care. For example, following her knee and hip replacements Mildred required physiotherapy but the service was unavailable through home care.

It was hard on her, she found it very hard, she couldn't even get to the bathroom, and we had to take her all the way in to the hospital...I thought that was kind of unfair, there should be a service where the physios are on the road a bit, or even a physio aid.

During the years that Mildred lived in assisted living she began to have heart problems, which led to several heart attacks. Eventually, Mildred was not well enough to return to assisted living and the process was started to have her

placed in a nursing home.

[T]here was a waiting list when Mum lingered in the hospital for a couple of months waiting. It was really hard on her, because she was just there. She had lost it because she didn't know where she was or anything, so it was hard on her. They had to keep putting her into a room by herself, because she would get up in the middle of the night and she would be making noise and stuff.

Although Maggie is pleased with the care that Mildred receives, she remains upset over the process of placing her mother in a nursing home.

I do have complaints about the whole system of getting Mum put into a nursing home. The whole way that system works.

You have no say about where she's going to go, or very little say about where your parent is going to go in terms of, when they're in the hospital especially. When you get to the top of the list, [you go to] whatever bed opens up, as long as it's within 100 kilometres.

Maggie does not currently provide physical care for her mother in the form of assisting with feeding, bathing, or administering medication, but her caregiving work is nonetheless exhausting and time consuming. Maggie's role as a caregiver involves coordinating Maggie's institutional care, communicating with her family, and helping Mildred remain socially active. Part of caring for Mildred has necessitated that Maggie advocate for Mildred's well-being within the health care system. Maggie describes a time that she had to fight not only for appropriate care for Mildred, but

also for her life.

[I]f [mom] has a cardiac arrest she wants to be left alone and not resuscitated. But if she has a heart attack and doesn't arrest or whatever, she wants to be treated. And people seem to have a hard time dealing with that with an 89-year-old, because they feel that at her age she should be just left alone. So my sister and I had a really hard time with the doctor in Emergency one night, a really hard time getting him to understand that. . . because we didn't want them to just make her comfortable, we wanted them to help her with her heart attack and they didn't seem like that was in their minds. Like they weren't going to treat

her aggressively, I guess that's what I'm saying, like their policy is to not treat aggressively...

One of Maggie's greatest difficulties was learning about what services were available to her as a caregiver. She believes that caregivers could be greatly assisted by a centralized government agency that would provide information to caregivers, to relieve them of the frustrating process of searching for services on their own and trying to determine what is available.

There's no information like that so you're kind of staggering through, like staggering through fog, you might run into something and you might not...

Maggie has established boundaries that have allowed her to develop and maintain personal relationships. She thinks that caregiving within the lesbian community is unique, a belief

which stems from a deep sense of caring in the community and from a cultural expectation for families take care of each another.

I think [caregiving] can fall to them because they are 'single' and they're a woman...I think that lesbians, because they're women, end up being caregivers. If there is a couple, like what happened with me and my ex, you know, you both end up being caregivers rather than just the one, just the daughter... I think that women are brought up to be caregivers and nurturers anyway. I've also seen a lot of caregiving within lesbian couples, you know, end up caregiving for one or the other...I think the biggest difference is that you are coupled with another woman, and there

is some care there that we tend to understand. . . I tend to understand more about the caregiving that needs to be done than a man does.

While Mildred knows that Maggie is a lesbian, her memory has deteriorated, and this memory loss has meant that Maggie has had to come out to Mildred on a regular basis and reassert her sexual orientation.

[I tell her] "Well, I'm not interested in men, I would like to find myself a good woman though," and she[says]: "Oh, you're not one of those, are you?"

Maggie is regularly faced with Mildred's homophobia and in a way part of Maggie's life has become invisible because her mother does not retain this information. Maggie says putting her mothering a nursing home felt "like the last step" and she feels as though she loses a bit of her

mother with each visit.

It was like, well you know this is it for Mum, this is it; she is going to die here. I mean I've had, I've been grieving her, and grieving her, and grieving her this year, like every time I go see her I come back and I'm grieving some more. A lot of grieving, I miss her.

It is unlikely that Maggie will ever stop being primary caregiver as long as her mother needs care. Although Maggie found it difficult to accept the role reversal with her mother, she has adjusted to the change.

It's a big deal to switch from being the daughter to being a mother, you know what I mean? That's what you end up being is a mother to your mother. It happens gradually so it's not like overnight you're

switched. It happens gradually, but still when you sit down and think about it, it's very hard. Because all of a sudden the person that you've depended on to be there for you, is now depending on you.

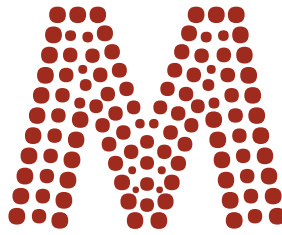
It has not always been easy for Maggie to take on this role, especially through her own illnesses but it appears to be a role that she has grown into over the years and is still able to enjoy the relationship she has with her mother.



Melissa's Portrait

"You have to be willing to give what you have to give, in order to make it work."





elissa is a 40 year old Caucasian lesbian who is the primary caregiver to her mother, Rosemary. Melissa and Rosemary live together in Halifax, where Melissa is enrolled in graduate studies at a local university. Rosemary is 72 years old and has been living with Melissa for the past sixteen years. Rosemary was employed by the government of Nova Scotia for twenty-eight years, and retired over ten years ago. Shortly after her retirement, Rosemary was diagnosed with Parkinson's Disease. Her health has steadily declined: she now requires a walker for mobility, and her speech is difficult to understand. A few years ago, Rosemary was diagnosed with colon cancer and underwent surgery to remove a tumour. Despite her frail health, Rosemary is a pleasant woman who entertains herself with television and movies, and enjoys visits from her family. Rosemary and Melissa share their home with Susan, Melissa's 52 year old partner. Susan is currently

on disability insurance due to an injury and provides care for Rosemary when Melissa is occupied with school.

Melissa has been a caregiver since childhood, taking on many responsibilities as she was raised by her mother and maternal grandmother in a small town outside of Halifax. When she reached adulthood, Melissa moved to Halifax; her mother moved to the city shortly after. Initially, Melissa and Rosemary lived separately, but when Rosemary began to have health problems, she moved into her daughter's home. Before long Rosemary's Parkinson's-like syndrome, colon cancer, diabetes, and high blood-pressure meant her ability to care for herself was severely diminished, and she became reliant on Melissa's support.

Melissa is now Rosemary's primary caregiver, with an extensive list of responsibilities to ensure that her mother receives good care. Rosemary is able to wash herself, but she requires assistance getting in and out of the shower, and bathing supplies

need to be arranged in advance for easy access once she is inside the shower. Melissa cares for Rosemary's grooming, and often assists her with getting dressed. Rosemary has difficulty eating, and Melissa ensures that her meals are prepared to the appropriate consistency. Melissa assists Rosemary with mobility around the house, as she is prone to falls, and helps her navigate when they venture outside. Melissa explains her role as a caregiver as encompassing the basic tasks of daily life:

Even something as simple as changing the battery in her [...] battery operated toothbrush, I change that, I mean [...] you name it, I do it all.

Melissa feels that her mother's health and social well-being are very much in her own hands, and she finds this responsibility overwhelming at times.

... you are at times playing with someone's life, you

are forced to play God with someone's life. You have to decide what kind of life they have, what quality of life they have, where they get to live, basically essentially when they get up, when they can go to bed, when they eat, when they don't eat. That's an awful lot of power.

In addition to assistance with basic personal care, Melissa is responsible for purchasing Rosemary's everyday items, in addition to gifts for her to give on special occasions, such as Christmas and family birthdays. Melissa also tends to all of Rosemary's finances and has power of attorney for her affairs. Melissa cares for her mother's social and emotional needs, making arrangements for other family members to visit with Rosemary in her home. For Melissa, caring for her mother means ensuring that she receives intellectual stimulation each day, usually through current movies,

newspapers and magazines.

Melissa is careful not to leave Rosemary alone for too long, as she has difficulty walking, and cannot get up by herself if she falls. When Rosemary falls while home alone, she uses a cordless telephone attached to her walker and calls Melissa's cell phone. Over the years, Melissa has had to leave classes and exams to return home to her mother in such emergencies. Susan often helps Melissa care for her mother, particularly when Melissa attends school. As Susan no longer works outside the home due to a disability, she is often available to drive Rosemary to medical appointments, make her lunch, and assist with additional caregiving tasks.

Melissa explains that she cares for her mother because of a strong sense of duty toward her family. She believes that long-term care facilities cannot meet her mother's needs. However, Melissa does express her frustrations about being a caregiver:

I know I find frustration

a lot of times, because as a caregiver there is a lot of frustration, distress, in not being able to go out for a few hours in the evening or to go to dinner. Maybe meet somebody that might potentially be friends, but then you have to say, oh I'm sorry it's 5:30, I have to go home. Your time schedule is very restricted... babysitters are easier to secure for a child than for an adult. People with a sick child could sympathize.

Over the years of caring for her mother, Melissa has had a lot of experience dealing with the health care system. Although Melissa would qualify for limited home care and respite support, negative experiences with and impressions of support services have prevented her from seeking outside support



in caring for her mother.

According to the province of Nova Scotia they will allow you so many hours of personal home care every week, and so much respite care a month, if you want to access that. But I would have to renegotiate my life, on other people's terms...I'd have to deal with health care workers coming in and I've been told when I did actually inquire about it, that it's no guarantee that I would get the same person, and I would have to reiterate and continually explain the history of my mother's illness to each new person.

Although Melissa has decided to care for her mother without any formal support, she expresses resentment that her family and

community have not supported her in her caregiving role. For example, Melissa's brothers live outside the city, and provide no financial or physical support in Rosemary's care. Similarly, Rosemary's sister provides Melissa with little support. Melissa recalls one time that her aunt agreed to look after Rosemary for a day:

I got a phone call from her on my cell phone about a half an hour before we were actually back in the city, asking us how much longer we were going to be. Because her stress level was so high, just having to negotiate dealing with my mom for one day, one day, and she has never done it again.

Melissa feels that she has received a tremendous lack of support from health care providers, and that her sexual orientation is often more important to health care providers than the care that she provides to

Rosemary.

People will think it's okay to ask me, "Well how does your mother feel about you having your alternative lifestyle going on with your female partner in the household?" I've had people ask me that question – professionals. [...] Why is my sexuality relevant?...You know, my living arrangements really are no different. Other than knowing that there's two grown adults here to look after her care, I think that's the limit of what you need to know. And that she's being looked after twenty-four hours a day.

Melissa has had to negotiate with health care professionals regarding

the composition of her family.

My mother was in intensive care unit different times, over the last several years. And intensive care units of course allow only immediate family members to visit the person who is ill, and we had to negotiate whether or not my partner [Susan] who I deem as family is allowed to participate in her recovery and her care. And that makes it more stressful for everyone; makes it stressful for her [Rosemary], it makes it stressful for me, it makes it stressful for my partner, and anyone else in my family, to have to deal with these things. And if you're trying to deal with all of that, on top of just trying to deal with the

impact of serious chronic illness, it compounds the problem.

Melissa believes that her experience as a caregiver for her mother would be greatly improved by a health care system that would appreciate the complex ways that sexual identity affects caregiving.

Let's change, let's also change the photographs and pictures in waiting rooms, from man and woman with a little child on the wall to different diverse groups. Let's change how you have these things set up, let's change how the sensitivity of the professionals are being taught, from year one of their training. Let's not assume that everybody who walks in the door is white, heterosexual and male; or a white, straight

woman.

Melissa's role as a full-time caregiver has impacted her life in many ways. Her education has been interrupted at times, and she has been unable to work outside the home. Melissa's relationship with Susan has suffered a result of caring for Rosemary. In caring for Rosemary as her illness progresses, Melissa feels the loss of their close mother-daughter relationship.

I mean at one time my mother was one of the people I would go to for support, advice, or assistance and help. I was the child, and she was the adult, and now it's reversed, she's the child and I'm the adult. Now I'm the one who's relied on for advice and support, and assistance.

Despite her continued sacrifices to care for her mother, Melissa believes her own identity to be intimately linked to her role as a



caregiver.

I doubt I'll ever change... There is no respect, there's no recognition, there's no payment, there's no pension, there's no benefits, nothing that most other people strive for, live for in their lives. You know things that give people satisfaction from the society in which they live, the community in which they live, people say 'That's so and so they're the doctor, or they're the lawyer, or they're the chiropractor, or they're the nurse, or they're the fire fighter, or they're the librarian, or they're the police officer, or they're the teacher,' they're the something. I'm none of those things. When people see me it's, she's umm,

she's, what is she? Who is she?

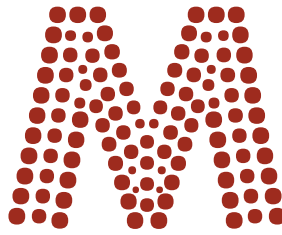
For Melissa, her duty to her family and her role as caregiver will always prevail.

She's my mother, which is why I try so hard. And the fact that I know that the person that I know her to be, she would do the same. My mother would never have left me. And I'm sure that if I was in the same position, the situation would not be any different... It's called commitment, you have to have a commitment to do things. You have to be willing to give what you have to give, in order to make it work.

Mingmei's Portrait

"I feel like I'm a teacher, I'm a daughter, I'm wife, I'm psychologist...I'm everything."





Mingmei is a 47 year old immigrant woman who is the primary caregiver for her 78 year old father, Mr. Shen. Mingmei has lived in Canada for seven years, having migrated from Asia over fifteen years ago. Originally from China, Mingmei earned a PhD from a Japanese university and now works for a non-profit organization in Halifax. Mingmei is a very active and independent woman, interested in a holistic way of life to balance her physical, mental, and spiritual well-being. When her mother passed away four years ago, Mingmei became concerned about her father's ability to live on his own, but he was not ready to leave China. Years later, when Mr. Shen agreed to move to Canada, Mingmei immediately began the process of sponsoring her father to immigrant to Canada. The application process for landed immigrant status lasted nearly two years, and throughout this time Mingmei spent considerable energy worrying about her father's health. When he arrived,

Mr. Shen had no comprehension of the English language and had no other friends or family in the country. Mingmei's story of caring for her father serves to deepen our awareness of the intricacies involved in providing elder care for a newcomer parent.

Mingmei did not have the opportunity to spend a lot of time with her father while she was growing up, as he was subjected to prolonged harassment and arrest during the Cultural Revolution. In her father's absence, Mingmei cared for her sick mother and brother. She prepared meals, monitored daily medications, administered injections and provided moral support. At this young age, Mingmei also coordinated medical support for her mother and negotiated interactions between the government and her family.

When I was only nine I lost parents for few years. But that time I had to learn the change, the big change. No parents to help you and no school to

go but you have to be a parent because you have responsibility to take care of your younger brother and you have to learn to cook, you have to learn everything in the house.

Prior to his arrival to Canada, Mingmei had only seen her father three times since she left China over twenty years ago. In the mid-1990's, Mr. Shen's eyes were damaged when he was beaten by Chinese authorities. His retina was recently replaced and he now requires eye drops once a month and needs assistance to perform small tasks before his vision returns to normal. Mingmei's role as a caregiver for her father encompasses many tasks, from assisting with integration into Canadian society, to managing household chores such as cooking, cleaning and doing laundry, and arranging medical appointments. Mingmei also provides her father with financial support, housing, transportation, translation, and cross-cultural interpretation. Caring for her father has meant a

series of additional responsibilities for Mingmei.

Now I feel like I'm a teacher, I'm a daughter, I'm wife, I'm psychologist because I have to use different way to give him some understanding the new culture, new life how to deal with. So I think I'm everything. I'm a cook, chef, laundry, or cleaner, or everything for him.

In caring for her father, Mingmei finds it difficult to have conversations with him and determine his needs. Mr. Shen becomes particularly agitated when Mingmei attempts to explain cultural differences.

He doesn't want to talk to me about anything else. Even "I'm hungry" or "Can you-?" The food may be too salty, may be too something. Never say

anything. If I ask [he says] "Whatever." That is his answer, "Whatever." It has make me uncomfortable I don't know whether to be angry or be what, because I really don't know what to do or how to do. Because always, if I ask him ... [no matter] what I ask, "Whatever." No conversation. So that makes me really crazy.

This lack of verbal communication was initially very difficult, but over time Mingmei developed ways to communicate with her father without being disrespectful.

I will put some like either some Chinese little bit of sweet, or some fruit, like a snack. I don't say anything, just [moves hand as if giving him something and then going away] ... Later I check if

he eat or drink, so that will be a special communication [to] let him know, "I care about you." So give him a sign that I always think about him.

Preparing food for her father occupies a considerable amount of Mingmei's time. In the morning before work, Mingmei boils water for the morning tea and helps her father prepare breakfast. In the evenings after work she prepares a snack and then cooks dinner, usually saving leftovers for Mr. Shen's lunch the following day. On weekends Mingmei spends her time cleaning, doing laundry and cooking special Chinese food that her father enjoys.

Mingmei has felt concerned about her father's social and emotional well-being, and she has made efforts to prevent him from feeling lonely or isolated. On a few occasions she organized gatherings with other Chinese people who live with their elderly parents, but her father was not interested in meeting new people.



Mingmei has encouraged him to develop a daily routine and to take walks in the morning, and she enrolled him in an ESL school for Newcomers. She works to maintain her father's social connection with his family and friends in China, and she taught him how to access Chinese newspapers on the internet, although he is only able to read from the computer for a short time before his eyes tire.

Mingmei's responsibility for her father also takes the form of coordinating medical care. Soon after his arrival in Canada, Mingmei persuaded Mr. Shen to see a doctor. This visit resulted in a series of tests, x-rays and ultrasounds which found problems with his kidneys, thyroid, cholesterol, heart, eyes, and hearing. Since then, Mr. Shen and Mingmei have had a series of interactions with the health care system. Overall, Mingmei has been pleased with their interactions with hospital staff and their family doctor, but she expresses discontent with lengthy waiting times.

Mingmei also emphasizes the need to work towards an

integrated health care system that is both accessible and relevant to the needs of diverse cultures and newcomers in Halifax. She raises the need for a more integrated cultural health translation and interpretation service within the medical system. Her experience reflects the importance of accessing the service of an independent trained professional to assist newcomers who are not fluent in English. Mingmei was aware of the cultural health interpreter service available in Halifax, but she feels that there is still a long way to go to integrate these services within the health system to better serve the needs of newcomer caregivers. Mingmei chose not to access the cultural health and interpreting service for two main reasons. First, she feels that the service was logistically difficult to access.

The system is not convenient because the interpreters don't work in the hospital. They are somewhere in the community. When you

book an interpreter it does not mean that if you have to go tomorrow [to the appointment] you will have the service.

Secondly, she recognizes that the random selection of an interpreter is a limitation of the cross-cultural health interpreting services. Individuals coming from the same country do not automatically trust each other. People coming from the same country may differ in their values, economic and social backgrounds and political views. Mingmei also highlights her concern that the doctor's lack of awareness of her father's past experiences prevented him from having a thorough understanding of Mr. Shen's physical and mental health.

For many, many years he wasn't allowed to say I have a headache, or stomachache or something. Maybe that is the problem. But the doctors they can't

understand that part.

Mingmei recognizes that immigrating to a new country always poses new challenges and responsibilities for newcomers. She also believes that as a country that boasts multiculturalism, Canada needs to develop on-going programs to facilitate the integration of new members into its society. She specifically sees the need to create services to support immigrant caregivers, including health care and educational programs to familiarize service providers to the newcomer's diversity of experiences and backgrounds to better serve their needs.

Mingmei spoke about the importance of raising awareness of the caregiver's contributions to our society and expressed her feelings about the lack of appreciation and government support for the work caregivers perform. She feels that caregivers should be paid, as remuneration would validate the work, prevent financial strain, and allow for a better quality of life for both the

caregiver and care recipient.

Whether caregivers work for pay or provide full time care, they need respite support, financial support, training and education support. The government needs to develop a sound program to let caregivers know they are supported.

Mingmei suggests that remuneration is one way to support and recognize caregivers work, and that the government could further provide financial support such as access to a drug plan for those who cannot afford health insurance, funding for educational and training programs to support full time caregivers, and funding programs directed to newcomer immigrant caregivers to facilitate their integration and awareness of available health programs.

Providing in-home elder care has had a profound impact on Mingmei's life, and she often jokes that she is experiencing more

culture shock than her father. Caring for her father has been a stressful undertaking that has significantly affected her personal time and her responsibilities at work.

I have to arrange my work time with him, then we can go to see doctor or hospital to take all the [tests], because everybody has the regular working hours. I don't have other people to do that for me, for my father. . . That day maybe I already booked long time ago for a meeting, but the doctor's you cannot change because they are so busy, only one spot for you. What am I going to do?

Mingmei feels that the stress related to the limitations placed on her freedom coupled with caregiving demands have affected her health and well-being. She neglected her own health and lost



interest in doing crafts, listening to music, visiting friends and eventually suffered from physical and emotional strain.

Last week I was sick. I never [used to get] sick. Three days I couldn't move just on the sofa. I couldn't get up from sofa and all that is only the stress. . I never get any flu, so I always proud of myself so healthy so strong but now is so different.

Mingmei would like to learn from other caregivers who have more experience providing in-home elder care, and in particular the strategies they have developed for coping with emotional strain.

Her newcomer status has had significant impact on Mingmei's work as a caregiver. In her reflections she raises elements of culture shock, an intergenerational gap, and role reversal as having affected her relationship with her father. Mingmei has undertaken

the role of a mother, teacher, daughter, wife, and psychologist to her father. She also experienced the role of a settlement worker by helping her Dad enroll in the ESL school, finding him a family doctor, teaching cross-cultural awareness, and translating conversations. Performing these non-traditional roles created uncomfortable situations and increased Mingmei's work as a caregiver. The absence of an extended family is yet another hardship that Mingmei faces in her work as a caregiver to her father.

There are many reasons for Mingmei to continue to care for her Dad. She displays a strong sense of obligation and responsibility to care for her Dad in his elder years, and was raised to accept responsibility and value interdependence and reciprocity. Mingmei values the cultural and moral Chinese norm to care for her father in his vulnerable elder years, and she believes it to be her duty as a daughter and eldest child to provide his care. In addition to her obligations to care for her father, Mingmei cares for

her father because she loves him and wants the best for him. She has witnessed his suffering and would like to see him enjoy his last years in relative peace.

I remember my father said as the children you have to take of your parent, doesn't matter their health or not. I still feel that is good. I don't like Canadian way. After eighteen years old they go their own, of course the parents let them to be independent and then. . . never coming back to take care of parents, I mean mentally. That part I like Chinese culture you are always part of your parents physically and mentally so then that part. . . that is your duty you have to do.

Patti's Portrait

"In the Mi'kmaq language there is no such thing as disability."





Patti is a First Nations (Mi'kmaq) woman who lives on a reserve in Nova Scotia with her two children, Billy (12) and Ruth (14). In addition to being self-employed and an active member of her community, Patti is a full-time caregiver to her son who was born with tuberous sclerosis complex (TSC). TSC is a rare incurable genetic disease that causes benign tubers to grow in the brain and on other vital organs of the body. Over a four month research period, Patti shared her experiences of caring for her son and explained the unique way that being a First Nations woman has not only shaped how she cares for Billy, but also affects the support she gains from her family and community. Patti's First Nations caregiver identity has been important for her own spirituality and her interactions with the federal and provincial health care systems.

Prior to having children, Patti had no experience as a caregiver. She had grown up on the reserve with her family and spent some

time in Halifax when she reached adulthood. Following the birth of her first child, Patti moved back to the reserve where she benefited from a supportive family and community network. During her pregnancy with Billy, Patti learned that two tumours had been detected in her baby's heart. A clear diagnosis was not provided until she delivered her son, when tests revealed that Billy had tuberous sclerosis complex. Given the rarity of the condition, little information about the progression of the disease was available, and Patti was left with unanswered questions and unalleviated concerns. Feeling as though she were a player in some "kind of a guessing game," Patti quickly recognized the importance of placing her own fear aside in order to effectively care for Billy. Nurses showed Patti how to administer Billy's medication by needle and demonstrated strategies to manage his frequent seizures. Patti recalls the independent research necessary to learn more about the disease.

The doctors were good but

I just wished that they would have known more at the time. That's when we took it upon ourselves.

Patti's role as a full-time, primary caregiver for Billy has taken many forms over the years as Billy has grown from an infant into a child. Throughout Patti's stories, the most frequent forms of caring that she shared were related to constantly thinking of her son, anticipating his needs, and making decisions about his health care. Despite initial medical predictions that Billy would never be able to walk, he surpassed all expectations and is now able to walk, run, and swim. Billy has good coordination with both gross and fine motor skills, and while he does not communicate verbally, he is able to communicate in ways that those close to him can understand. At the time of this research, twelve-year old Billy was a physically healthy boy, despite his disease and relatively limited capacities.

Billy is home with Patti 24 hours a day. He used to attend school, but his condition leaves him prone

to aggressive and self-destructive behaviours, and he was asked to leave the school because of their zero-tolerance policy concerning violence. In their home, Patti tries to encourage Billy to be as independent as possible with his personal care, and with Patti's guidance, Billy is able to do quite a bit for himself. Although there is no typical day for Patti and Billy, there are regular routines such as eating, bathing and dressing.

When he gets up in the morning most times it's changing as you would a small child. He requires toilet training, so of course you're going to be dealing with situations where you do have some accidents. Same with feeding, it's assisted feeding. He's getting much better using utensils, but needs guidance.

Ensuring that Billy is comfortable can be a very difficult aspect

of providing care, particularly because Billy communicates only through physical motions, facial expressions, and sounds. Patti often needs to go through a process of elimination in order to understand what Billy wants, and in turn Billy often expresses his frustration through aggressive or self-destructive behaviour which Patti tries to manage.

For Patti, caregiving means assisting her son with basic tasks, while patiently negotiating and monitoring his behaviour. For example, during one research observation Billy removed his clothing in the family van. When they arrived home, Patti helped Billy put his shorts back in a seemingly complicated process of cornering him and trying to keep him still. She held the shorts in her hands, told him to place his leg into the holes, pulled his shorts halfway up and then gently tapped him on his upper legs while telling him to pull his shorts up. She did this a few times until he finally grabbed the waist band and pulled them up over his bottom, with some assistance. Once they arrived in the house, Patti sat

Billy at the table and placed his food on the table just out of his reach, in an effort to encourage Billy to eat with utensils rather than his hands. She loaded the tablespoon with food and handed it to him, while shielding the plate with her forearm to prevent him from grabbing the food. Billy soon began to make noises that Patti recognized specifically as a request for a drink. Billy got up from the table to open the refrigerator, just as Patti moved over to close the door. Billy then opened the freezer door, and Patti again closed the door and led Billy back to the table. To indicate that he was finished with his lunch, Billy pushed Patti's hand away, which signaled a new task to Patti as she immediately got up from the table and told Billy that he had to "sit on the bowl" as part of his toilet training. They entered the bathroom and Patti pulled his pants down and told him to sit, but Billy tried to push his way out of the bathroom. Patti was able to hold him back and eventually managed to seat him on the toilet. She stood close by to ensure that he did not get up off of the toilet. Observations such as these



highlight the extent to which Patti is engaged in a constant process of caring for her son.

While in the family home, Patti, Billy and Ruth are able to manage with their own familiar routines, and adjust to Billy's periodically difficult behavioural episodes. Patti tries to include Billy in as many activities as possible outside of her home, as she appreciates the importance of contact with their family and friends. Billy is comfortable with the social network known to him, but his behaviour is often aggressive and unpredictable around strangers. In caring for Billy, Patti must manage his contact with strangers and their reactions towards him, a responsibility that might involve calling a restaurant in advance to minimize the waiting time for their meals, or managing angry hotel guests if Billy misbehaves when the family spends time vacationing off reserve.

Patti has had several experiences with provincial and federal governments and health care systems. While most of her experiences with health care

providers have been positive, Patti stresses the need for increased access to services on the First Nations reserve that are available in the city. On the reserve, Patti recalls one occupational therapist in particular who was very helpful, but due to reasons such as the therapy agency's high staff turnover and Patti's home location, these visits were initially inconsistent, and were eventually withdrawn. Patti's greatest frustration with health care services stems from the lack of local long term services. Patti explains that she is ineligible for services through Mi'kmaq Family and Children's Services or Indian Affairs. She is concerned about where Billy would be placed if she were unable to care for him. Patti does not want Billy to live off-reserve, but there are no long term facilities, such as a small options group home, on reserves for First Nations children.

There was a moratorium, where First Nations could not open up group homes. . . The government typically wanted to send

the kids, whether that be an adult child or youth, into institutions that were away from the reserve. . . I'm not going to compare it to a residential school but it's not far from it. . . It is my main goal, certainly, to hold the family together and to pursue a home for Billy.

Patti feels great frustration and anger that the government will provide for Billy only if he is neglected, abandoned or abused. Patti explains that if she lived in a city, her son would have access to social services and health care services that are locally unavailable, but these services would not be culturally appropriate. Patti is adamant that First Nations children who need services should be able to receive those services on reserve.

I mean come on, the existing [programs] are non-Native institutions or

services that do not reflect any cultural relevance. Whether that be Mi'kmaq or Aboriginal overall, I mean and that's extremely important in caregiving. . . I made attempts with the Department of Indian Affairs, the Department of Health, the Mi'kmaq Family [and Children's Services] . . . certainly thought that if anywhere we'd fall under that agency. The bottom line was, directly from Indian Affairs they admitted there's a gap. That gap is from 0 to 19 years of age. . . When children turn 19 they fall under institutional care. Prior to that age, they don't fit, First Nation children don't fit anywhere. . . [A friend was looking for help with caring for her son who has

autism] The bottom line was, she would probably have to neglect her child, abandon her child. Then Social Services would kick in...

Patti's frustration with the system has meant that her role as a caregiver has been met by her role as an advocate for her child's well-being.

It is extremely hard, but that's where you really can't give up... I mean I'll give as much as I can give to caregiving and I really don't mind that because I'm a parent. Not because I have to, but because I want to. But, I really believe that there is an obligation from the government. It doesn't have to be financial, it can be supportive services.

Since Billy requires 24 hour care,

Patti's life has been significantly affected by her caregiving role. Patty has few regrets, but she does feel hurt that many of her friendships have changed, primarily because she is always with Billy.

It hurts when you feel like you have to shut yourself, you and your child, out... If I had a visitor that came from elsewhere, he would not be impressed. But it's getting better. I've warned him, like you know he's going to seem like he's not welcoming to strangers. I want them to come back, you know what I mean?

Although Patti's caregiving tasks necessitate sacrifices with her personal interests, she nonetheless expresses fulfillment with her role. Patti believes that caregiving in the First Nations context is unique particularly because of its inherently close-knit, supportive family networks. Patti credits her First Nations culture with



providing a supportive and encouraging environment within which to provide care to Billy.

The family is very traditional, and I guess with traditional would be spiritual. Spiritual meaning there is a lot of sweats that my brother does and my sister does. . . Then there is the medicinal like that also is part traditional, like my sister and mom make medicines. And some of the medicines are made for Billy. . .

Attending sweats and other spiritual ceremonies provides Patti with guidance and reinforcement for her efforts as a caregiver and as a parent.

I don't go to church. I go to sweats. I am practicing [spirituality] when medicines are being made

because they are being made for Billy. I guess what it does for me is it helps with the reassurance of doing what is possible, but under true belief.

Patti recalls her grandmother and mother teaching her to respect all people regardless of their abilities:

But we were always told, when you see children like Billy. . . you take the time to appreciate the parents with that child and to acknowledge the child. Make sure that you're visible to them, and they don't feel any different in their surrounding... I think in the Mi'kmaq language there is no such thing as disability. There's always ability, right. There's more focus on what you can do,

not what you cannot do.

Despite the challenging aspects of providing physical and emotional care to her son, Patti is adamant about the joy she receives from caring for Billy and having him in her life. Patti is not opposed to placing Billy in a long-term care facility, as long as it is within a First Nations community. Until such services become available, Patti will continue to care for her son and enjoy the rewards her caring brings to them both.

Oh my God, when you see him smile! Oh it's, he's got this radiant smile, radiant laugh and this radiant smile! . . . It rewards me sometimes, you know what I mean? Because ultimately, I think that's what you want is to see him happy.

Paula's Portrait

"I do it because he's my son."





Paula is a 37-year-old Mi'kmaq woman who lives in rural Nova Scotia with her husband, Charlie, and their three children. Although Paula refers to her work as "mothering," Paula is a full-time caregiver to her eldest child, Thomas, who was born with Spina Bifida. Paula and her family live off-reserve, in a small two bedroom trailer located in a mini-home park. Paula is an optimistic woman who enjoys writing short stories and poetry, going for long walks in her neighbourhood, and doing volunteer work at her children's school. Charlie is non-Aboriginal and employed full-time at a local factory.

Paula and Charlie learned that their first child would be born with Spina Bifida shortly before his birth. When Thomas was born, Paula and Charlie opted for a surgical procedure that could save the baby's life. Thomas survived the surgery, but he remained paralyzed and his bladder, kidneys, and bowels were all compromised. In the days following Thomas' birth, Paula recalls feeling bitter

and confused as she tried to make sense of his health.

In the beginning . . . I found it really hard. I was very moody then, but they [staff at the hospital] said it's like a grieving process. You go through denial and then you go through acceptance. And it's true you go through the fact that this couldn't happen to me, or why, anger, grief and denial, and it's all tied in...I don't drink. I don't smoke. I never did anything like that and here I have a disabled child.

As Paula spent time at the hospital with her son, she learned more about his condition and eventually began her own healing process. Paula and Charlie soon learned that by educating themselves about the disease, they could learn to care for their son and

enjoy his presence in their lives. Paula recalls that the hospital staff provided her with information, answered her questions, and remained patient through the difficult time.

Nine years later, Thomas is a quick witted, smiling boy in the third grade. He weighs approximately 200 pounds, has short spiky hair and dark brown eyes with wire-rimmed glasses. Although Paula is a full-time caregiver to Thomas, she describes herself as a mother first and as a caregiver second.

I am a caretaker. I call it a caretaker but I'm actually just the mom. I consider it just the mom because any other mom would be doing it too. . . I do it because he's my son.

Although Paula feels that her caregiving is part of her responsibility as a mother, the care that she provides for Thomas is different than the care she provides for her other two children. Thomas is paralysed from the waist down,

and each morning, Paula cares for Thomas by changing his protective undergarments, helping him with bathing, catheterizing him, assisting him with dressing, and preparing his medication. Paula describes a typical experience of caring for Thomas:


He wears a pull- up [undergarment] to bed because of his bladder and we change his pull-up. We catheterize him, which makes him empty his bladder out for school. They will do it again at school, I think at around ten o'clock and at dinner time – just to maintain his dryness, you don't want him sitting around in a wet pull up all day. So they [teachers assistants] go twice at school and they do it once in the morning and I do it when he comes home from school too, and then again after supper

and before bed. Just so that he's dry all the time... So the catheterization is a big part of his daily routine, because it's done about six or seven times...Every morning he gets his puffer, because he does have asthma, so he has to have his asthma medication. And then he has his medications...to prevent urinary tract infections, so he has to have that every single day. But he knows that too. It's so routine. We don't have to remind him to take that. Then he'll eat breakfast and we'll get him up into the wheelchair, and then the bus will come. It's a wheelchair accessible bus that picks him up, and picks the girls up. And then they're off to school, they leave at around 8

o'clock and they come home at two-thirty. So from eight o'clock to two-thirty it's quiet. It's very quiet.

When her children return home from school, the family often spends the evening at their community swimming pool. Swimming is an important form of exercise for Thomas, and it allows him to enjoy an activity like able-bodied children.

He says: "Look at me. I'm floating", and he floats on his back. He just thinks it the most wonderful thing because we're not there pushing his chair. He's doing it all by himself, and it gives him the feeling of actually going in the water and swimming. That's what he's doing basically, he's moving his arms, he's moving his hips. Oh, it's



amazing.

In arranging family activities, Paula explains that all outings revolve around Thomas and his needs.

[Caring for Thomas] is such a major part of my life. Everything else revolves around it. First and foremost he's the number one priority on my list because everything revolves around him. Where we go, what we're going to do, it's all based on whether he's feeling well, whether he's healthy...So ultimately where we go and what we decide to do is based on him first, and how he's feeling and what his needs are. It's such a major part of our lives. It's just what we do. I think if I was caring for another child

who wasn't my own and who was handicapped, I don't know if I could do it. I don't know.

Paula's caregiving work often involves being an advocate for her son. Paula recognizes the importance of Thomas's inclusion in recreational activities, and she appreciates the need for Thomas to develop his independence. Even though it is often difficult, Paula tries to act in the best interests of her son. For example, if Thomas needs something from his bedroom, Paula does not always retrieve it for him. Instead, she might ask whether he can get it for himself, a process that requires Thomas to drag himself across the floor to his bedroom. When Thomas is inside his home, most of his time is spent on the floor, because his wheelchair does not fit into many of the rooms. One of the family's most pressing needs is to make their home wheelchair accessible. Currently, Thomas must drag himself into the bathroom or into his bedroom because his wheelchair does not

fit through the doors.

For Paula, caring for her son means providing him with opportunities for social enjoyment and personal growth. In caring for her son and managing the family's financial constraints, Paula spends considerable time learning about organizations that provide financial support to families in need. Some of this support is aimed at Thomas' personal enjoyment. For example, Paula submitted an application to the Make-A-Wish Foundation and expressed Thomas's dream to swim with dolphins. Paula's application was successful, and the organization arranged for Thomas to live this dream. Other forms of financial support that Paula seeks are for needs more directly related to caring for Thomas. For example, Paula has arranged for one organization to assist Paula with costs of hospital trips to Halifax, and another organization provides some additional financial assistance. Paula explains her independent struggle to learn about organizations that could offer support.

We didn't have any help when he was first born because I didn't know about all these organizations. . . . I didn't know what was available. But through asking questions and word of mouth we heard about the Shriner's and we heard about the Spina Bifida Association, and who can help us.

Paula has been an advocate for Thomas to attend his local elementary school. One year before Thomas was scheduled to attend school, Paula approached the school to inform them about Thomas's circumstances.

I told them that I had a son in a wheelchair. I called the principal up and I explained to her. I said, "This is all new to me too, because this is my first child". And he's going into grade primary

and I don't know what to expect. She said, "Well we don't know what to expect either". She basically kept in touch over that year, asking about him, and I would explain to her what his needs were. She would bring us into the school, and try to make the adjustments, like for the bathroom, and for the wheelchair ramp, and making sure their school was accessible. It's an older school but it is accessible. They were great. But I gave them a year's notice, and she was thankful that I did.

With three children and a single income, Paula's family has considerable financial constraints. Paula and her children do not receive financial support from their Band because they live off-reserve. Paula has made several attempts to gain support from

her Band. Even her father, a well-respected elder in the community, has unsuccessfully appealed to the Band for support in Thomas's care. Paula explains:

Every Band is different. A lot of the time, it's who you know and who you don't know and what you say and what you don't say. It shouldn't matter where you live, you're still an Indian. Just because you live off the reserve and you want to make your life better, you shouldn't be penalized, but unfortunately you are.

Paula describes her decision to live off-reserve with her family as a double-edged sword:

I'm glad that we don't live on the reserve. In another way I kind of wish we did because I know what's



available, and what we could have, and how we wouldn't be struggling from pay cheque to pay cheque. But at the same time, I see the heartache and the drugs, and the booze, and all that goes along with some Native communities, unfortunately. So it's kind of like you're weighing the scales as to what you want. You know you want the best for your children and you probably don't want them in a system or a society where there's a lot of alcohol and drug abuse. So even though I would want to live out there, at the same time, I don't want to live out there. You want your children to be safe, and there is so much drug abuse, and so many younger kids taking pills, and using drugs, it's crazy.

Do I want them around that? No. Do I want to live up there and have everything paid for? Yes.

Paula considers her experience as a caregiver to Thomas as quite positive and rewarding. She had originally intended to return to work following Thomas's birth, but she and Charlie later decided that it was best for Paula to stay at home and care for their son. In her role as a primary caregiver to Thomas, Paula is grateful to the emotional support that she receives from her family. Paula and Charlie enjoy a close and supportive relationship. Paula also has a very close relationship with her father, a caring man who provides her with both financial and spiritual support. Despite the challenges of caring for a physically disabled son, Paula finds being a caregiver and a mother extremely rewarding:

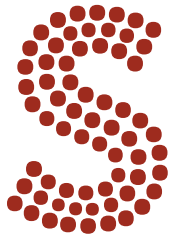
It's great being a mom. Caretaking has its days. When you're tired and you've had a long day and

you're cranky – but when they smile, and they give you a hug, and they kiss you good night, that's the greatest thing.

Serena's Portrait

"At one time, she had 265 appointments, I never missed one."





erena is a fifty-seven year old Black woman, born and raised in a predominately Black rural community in Nova Scotia. Serena now lives in a rural community with her husband and three of their grandchildren, in close proximity to her grown children and siblings. For the past thirteen years, Serena has been the primary caregiver to Tina, her thirteen year-old granddaughter, who was born with Spina Bifida.

Serena has a wide, warm smile and an inquisitive personality. She and her husband are very active in their community, particularly with the church. Their home is very welcoming, appearing to have come straight from a magazine cover, with high ceilings and marble floors in the kitchen and in the formal dining area. The stairway inside the house has a lift for Tina's wheelchair. Tina exercises some independence in her small bedroom, where she has a large bed with an overhead trapeze that she can use to move

herself into a sitting position.

Tina was born to Serena's teenage daughter, Carlene. After three months in the hospital following her birth, Carlene brought Tina home to be cared for by Serena, who quit her full-time job of fifteen years to care for her granddaughter. For several years, Serena cared for Tina while Carlene worked full-time.

That was her decision that she was well, "I'm going to move out." And the words to her was, "Well, how will Tina get looked after?" and the words to me from her were, "Well, Mommy, you know I can't look after her." But that was her words, "I can't look after her." I said, "But you can stay and be a part of her care." But young girls at that time, their way was the best way. So that's how I ended up

being her sole caretaker.

After Carlene moved out of the house Tina became Serena's full-time responsibility. At the same time, Serena's father became paralysed and required full-time home care. In the eleven months before his death, Serena and her sisters cared for their father in his home.

Myself and my sister had to take day shifts with him. I had to dress Tina, care for Tina, take Tina to my mom's place and care for Tina there and plus care for my dad at the same time. There had to be two people because my dad was big and heavy and he had to have two people, one couldn't do it. My mother was alive but she couldn't do anything to help. She got food and water and helped out that way, but when it came to

the lifting, the changing, we had to bathe our dad, as if he was our baby. We had to do all of that.

When Serena returned home after caring for her father, her focus turned towards Tina's physical and emotional care.

It was double duty. There were many times I found myself sitting you know after I came home. I would find myself and crying.

Since her father's death, Serena's full-time caregiving efforts have been directed towards Tina. While Serena has had positive encounters with medical personnel who spent considerable time answering her questions, she feels that the doctors were unsympathetic when Tina was born. The doctors predicted that Tina would likely be a "vegetable" if she survived. Determined to give Tina the best quality life possible, in the early years following Tina's birth, Serena and her husband spent

a great deal of time focused on Tina's physical development. For example, when Tina had difficulty learning to walk at fourteen months of age, Serena and her husband walked with her every day and every night. Serena has helped Tina learn to walk, and she has taught Tina the importance of strengthening her fingers and hands. These early efforts paid off, as Tina is now able to use her hands to eat meals, play with dolls, and use the computer.

Serena's perseverance has enabled her to seek out resources available to her to help her care for Tina's multiple needs. Serena credits staff at the children's hospital with ongoing support, especially during trying times.

You know, even when I would ask the doctor, he would say, Dr. Smith would say: "Mom, you are doing fine. Bring her back in six months time or a year's time." I would be so nervous, I would say:

"Doctor, can I bring her back in six months, you know?" "No Mom. I want to pat you on the back; you're doing great. You never miss her appointments." Tina, at one time, she had 265 appointments, I never missed one.

Serena undertakes numerous physical caring tasks throughout the day, beginning early in the morning when Tina wakes up. Tina attends school twice a week, and on these mornings Serena wakes up early to manage the morning routine. Tina uses a lift in the bathroom to help her in and out of the bathtub. After her bath, Tina rests on her bed where Serena catheterizes her, a procedure that Serena goes through four to five times a day. Once or twice a day Serena will do a rectal touch for Tina, a procedure that involves inserting her index finger into Tina's rectum to loosen up her stool. Serena then helps Tina get dressed and combs her hair, a process that usually takes forty-five minutes. Once Tina

is prepared for the day, she and Serena make their way downstairs for breakfast with support from a recently installed stair lift.

I have a lift in the ceiling, and after she's all bathed up and all dressed, then I hook her up to her lift, ceiling lift and bring her to her wheelchair and the lift sets her in her wheelchair. It's powered and you press it and it sets her in the wheelchair. After she sets in her wheelchair, you unhook her and let it go back up. And then she is in her wheelchair from her bedroom to the hall, in her wheelchair and then we can lift her. We can hustle her from her wheelchair on to her stair lift. She has a stair lift in now, which is really

helpful to me.

Before the lift was available, Tina struggled to climb up and down the stairs with Serena's help.

Usually I would use my knee, my right knee and let her sort of like set her bum on it and then [I] lift the knee up and help her up that way.

Serena now suffers from arthritis in her knee as a result of manually moving Tina up and down the stairs for three years.

Serena receives support in her caregiving from two of her grandchildren that live with her. Serena's sixteen year old granddaughter, Gail, has been particularly helpful with certain caregiving tasks. Serena is grateful that Gail has recently begun to learn the regular procedures.

She's very good with Tina. And you know I thank God for her because

if I really have to go out and stuff, she cares. I mean like nothing left major that she's have to do, that I don't do before I leave. I make sure that everything major is done and it's just some local stuff. She can come in and prepare anything for her to eat that she wants, give her anything to drink. She knows just about everything. It's just that there is no one here that knows rectal touch or knows the catheter. That is only given by me. That is the only thing, I am in the process now, as soon as school closes, I give Gail that training. I am going to train her how to do the catheter.

Serena's grandson, Edward, also lives with them and is attentive to Tina's needs. Edward was

initially jealous over the amount of care and attention that Serena gave Tina, but he has come to learn more about Spina Bifida and better appreciates Tina's special needs.

Throughout her thirteen years of caring for Tina, Serena has been faced with many gaps in both the provincial and local health care system. One of the most frequent challenges that Serena faces in accessing medical care for Tina is transporting Tina to medical appointments in Halifax. Since Serena does not drive and Tina is unable to travel on public transportation, Serena usually asks her neighbours for a ride at least one week prior to a scheduled appointment. Before participating in this research, Serena was unaware of special buses that she could access for her granddaughter.

Prayer is very prominent in Serena's home and she depends on her relationship with God to guide her through difficult times. Tina has a prayer partner who she connects with everyday after school, and Serena believes that

relationships and social activities keep Tina's spirits high.

Even though Tina can't do what other children do, Tina is a member of the junior choir, she goes to the church and she sings in the choir. She sits, everyone else is standing, but she sits. She claps her hands.

Serena keeps Tina closely linked with other people, especially her peers.

Tina does get a lot of attention from children, she gets a lot of love from children. At school, no matter where Tina goes, somebody wants to be near her. Tina is a very people person.

It gives Serena great pleasure knowing that Tina realizes that her grandmother provides her with excellent care.

When I am bathing her all up and she is laying

on the bed, putting all the lotion and stuff on her and her looking up at me with a big smile. And she's saying, "You're really looking after your little girl, eh Nanny?"

Grief sets in for Serena when Tina has to undergo surgery. For example, surgery was necessary when Tina needed a shunt inserted into her brain and had to endure additional operations. Tina took a long time to emerge from the anaesthesia and as a result, her recovery time was delayed. Hospital stays mean that Serena packs a suitcase for herself and spends most of her time caring for Tina.

Serena has considered respite care for Tina, particularly for assistance with her morning routine and for occasional time away with her husband. During the course of this research, Serena and her husband took their first solo trip in 13 years, travelling outside of the province while Tina stayed with her mother. Serena had



previously taught Tina's mother the necessary caregiving tasks. It was a big step for Serena to leave Tina for several days, but it served to enhance Serena's confidence in occasional respite care.

That means that I'll feel confident in leaving her as long as I'm leaving her with someone that knows her routine, that can do the catheterization, and rectal touch, and she's being fed and she gets, you know, her supplies and stuff that she needs; changed regularly because that plays a big part – 13 years old and she's never had a bum rash.

Serena voices concern over her own ability to provide consistent care for her granddaughter, as she has health concerns of her own. Serena has diabetes and arthritis and worries about Tina's well-being if she is unable to care for her in the future. Regardless of her

own health, Serena and her family remain committed to providing the best possible care for Tina.

I just love my job I am doing with her. I love caring for her and I just wouldn't, I just couldn't see someone else caring for her. If I had the skills to care for her, I just couldn't see someone else doing it.

Conclusion

The 14 portraits of the women caregivers provide ample narratives that have instrumentally helped the researchers better assess government structured services and programs.



The 14 case studies presented above contain innumerable ideas about programs, policies and services that might make these women's lives easier. If Canadians in fact care about the quality of life of those receiving care in the community, and about the quality of life – the healthy balance – of those who give care to loved ones, we are well-advised to heed the voices of these women. Below is a distillation of some of the policy-oriented recommendations that emerge from the 14 case studies. Each policy recommendation contains associated ones. The policy proposals are followed by a concluding section that discusses future research on caregiving in Nova Scotia.

1. Increase Provincial and Federal Government Financial Assistance Designated for Caregiver-specific Service Support Programs

- Hire more healthcare staff to cope with the burgeoning

aging population

- Establish more service provisions for rural locations
- Enable specialized care services for severe illnesses and disabilities at rural health facilities
- Introduce more social and health services for care recipients
- Create a drug plan for caregivers and care recipients who cannot afford health insurance
- Implement affordable transportation that assists both caregivers and care recipients to travel to and from medical appointments and all health service agencies
- Establish a centralized lending system administered through grants or loans for people affected by physical disability to utilize equipment on a temporary basis when

required

- Create 24-hour support services for caregivers and care recipients affected by disability
 - Offer bursaries for people affected by disability to employ their own attendants
- 2. Establish accessible integrated information and service provision systems for caregivers and care recipients**
- Better enable coordination and cooperation among health agencies, health service providers, and other organizations that support caregivers and care recipients
 - Prioritize a well coordinated system that interlinks services and professionals such as surgeons, nurses, family doctors, palliative care, social workers, home care, and continuing care in order to provide stable permanent health case-workers and accessible services for care

recipients

- Establish a centralized agency that would coordinate information on caregiving for caregivers in both rural and urban areas
- At the centralized agency integrate resources on available services for caregivers into personalized information packages
- At the centralized agency employ staff that would talk with caregivers about available services on a one-to-one personalized basis, and during such consultations staff should assess their personal needs, and assist them in making decisions on where/how to proceed
- Establish more accessible channels of information that explain services and funding available for caregivers and care recipients
- Establish more accessible channels of information that explain to caregivers how they

can obtain financial assistance for applicable services

- Establish more accessible channels of information and more support services for caregivers to write proposals for financial assistance
- Develop educational and training programs for full time caregivers that are delivered in modes and at times that make sense for caregivers
- Provide education programs for caregivers on specific health conditions, medication management, lifting techniques, stress management
- Establish opportunities where caregivers could learn from one another through dialogue about providing in-home care for elders or about strategies to cope with emotional strains associated with caregiving
- More workshops on caregiving should be delivered by caregiver associations, with financial and infrastructure

support

3. Establish an integrated healthcare system that is both accessible and relevant for immigrant caregivers and caregivers from all kinds of cultural backgrounds

- Establish more services that support immigrant caregivers
- Establish services specific to immigrant caregivers that account for their cultural diversities and varied experiences in caregiving
- Implement educational programs that would familiarize new immigrants with any locally available and/or relevant services/service providers
- Designate funding programs for new immigrant caregivers to both foster their awareness and utilization of available health programs
- Integrate within the medical system(s) cultural health translation and interpretation



services to expand on available translators and interpreters solely located in community-based organizations and settings

- Enable new immigrant caregivers to access services for independently trained professionals to assist those who do not speak English fluently
- There should not be random selection of cross-cultural health interpreters

4. Improve access to caregiver services on First Nations reserves that already are available in major cities

- Implement on-reserve long term caregiver-related services
- Implement services that are culturally appropriate for First Nations people, both on- and off-reserve

5. Appreciate how sexual orientation may affect

caregiving

- Change images portrayed in healthcare facility waiting rooms to depict different diverse groups of people instead of unintentionally portraying a uniform set of images that convey heterosexuality
- Introduce mandatory sensitivity training for professional health workers that draws on the experiences and expertise of gay/lesbian/bisexual patients and clients, family members, and health care professionals

6. Improve Home Care Services

- Stop the rotation of home care workers that each time must learn about care recipients from the primary caregivers
- Continuity of care required between home care workers and care recipients
- Primary caregivers need their own respite time to apply when taking home care workers

through the routines of their care recipients

- Home care organizations should be supported to be more flexible to meet clients' needs, especially as regards scheduled visits
- Physiotherapy, occupational therapy and other related allied/alternative health services should be available through home care
- Introduce on-the-road physiotherapy and occupational therapy services or aides who can address the needs of care recipients

7. Implement New Decision-Making Processes that Concern Care Recipients

- Redefine the age attached to all care recipient children in order to institutionalize more kinds of care services, especially for First Nations children
- Social Services should act on behalf of children that support their needs being

met within families and communities, before situations of abandonment or neglect are reached

- Primary caregivers in Nova Scotia require more input in determining how many hours of personal home care they can provide each week
- Primary caregivers in Nova Scotia require more input in determining how many hours of respite care they are allotted each month
- Primary caregivers require more input in deciding where their care recipients go upon entering hospitals and in how their loved ones are treated in hospital
- Care facilities including hospitals need to be cognizant that family has different meanings according to social and cultural context; the meaning of family for the patient/client must be respected

caregivers provide ample narratives that have instrumentally helped the researchers better assess government structured services and programs. They speak directly to realities placed on unpaid full-time caregivers. The ethnographies depict adult women from a variety of backgrounds that face entirely different circumstances based on either residing in rural or urban households with care recipients afflicted by a multitude of serious impediments. The participants of the Healthy Balance Research Program Phase #5 study are unpaid caregivers that have been placed in situations whereby they must assume a whole host of responsibilities almost every waking moment. The Portraits contain both extensive autobiographically narrated knowledge/experiences as well as biographical first-hand listening and observation. Their contributions to A Healthy Balance are indispensable, and their policy recommendations should also be acknowledged as invaluable and as most relevant in assessing and addressing the undervalued role of caregivers in Nova Scotia and

Canadian society as a whole.

Future research on caregiving in Nova Scotia could analyze how shifts from public to private healthcare are impacting caregivers' and care recipients' access to caregiver-specific services and programs. More work should be done with a greater sample of women primary caregivers and their recipients in order to better illuminate how caregiver issues need to be addressed foremost from the perspectives of those who live the experience(s). Only by drawing on the voices of those who experience caregiving first-hand, can the most appropriate, dignified, and resourceful policy programs and support services become ingrained into daily life to provide more care within primary caregiver and care recipient worlds.

The 14 portraits of the women





How does caregiving impact upon women's health?

How is caregiving rewarding?

What is demanded of caregivers in their homes?

What are the relationships between unpaid caregiving and paid employment?

These 14 micro-ethnographic case-studies provide rich and penetrating details from the lives of women caregivers from 7 different sociocultural groups in Nova Scotia...



“Now I feel like I’m a teacher, I’m a daughter, I’m wife, I’m psychologist because I have to use different way to give him some understanding the new culture, new life how to deal with. So I think I’m everything. I’m a cook, chef, laundry, or cleaner, or everything for him.”

“I am a caretaker. I call it a caretaker but I’m actually just the mom. I consider it just the mom because any other mom would be doing it too. . . I do it because he’s my son.”

“...The government typically wanted to send the kids, whether that be an adult child or youth, into institutions that were away from the reserve. . . I’m not going to compare it to a residential school but it’s not far from it. . . It is my main goal, certainly, to hold the family together...”

“There is nobody to fall back on, no caregiver assistance, there is none. You know you’re pretty much stuck. You go regardless, you know you just hope and pray you don’t get sick...”

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Research Program

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