ON RECIPROCITY:
TEACHING AND LEARNING WITH
PEOPLE WHO HAVE ALZHEIMER’S

by

Kathleen Downie

A thesis submitted in conformity with the requirements
for the degree of Master of Arts
Graduate Department of Adult Education and Counselling Psychology
Ontario Institute for Studies in Education
University of Toronto

© Copyright by Kathleen Downie 2011
Abstract

The initial intention of this arts-informed research study was to develop and implement art classes for people with Alzheimer’s disease, and to examine its impact upon new learning at cognitive, procedural and affective levels of experience. While these goals persist – indeed adult educational theory and quality of life are central to this thesis – the research focus gradually shifted from a constructivist view of the Alzheimer’s learner to a phenomenological view of the dynamic relationship between teacher and student. Its power to facilitate the growth of reciprocity and bolster identity within the learning context, whether one-to-one or in small group settings, became more apparent as the research progressed. This revealed the potential of arts-based educational programs to build mutual trust and reciprocity with and among the participants. In turn, these qualities contributed to the expression of positive feelings, improved self-esteem, sense of purpose and communication in people with Alzheimer’s.
Acknowledgements

My life’s work made itself known to me at the Hospital for Sick Children in Toronto, fifteen years ago, where I worked as support staff within the Division of Endocrinology. The combination of motherhood, part-time studies within the Faculty of Fine Art at York University, and my job at the hospital integrated my passion for the arts, learning and a longstanding interest in medicine. This merger ignited curiosities that caused me to wonder how I might bring my love of the arts to bear within the milieu of the hospital. Out of this questioning, my purpose met with that of Marcia Frank, a senior nurse educator within the diabetes clinic, who wondered how art programming at the hospital might benefit some of her clinic patients. With her advocacy and support, and that of Denis Daneman, Chief of Endocrinology, the Creative Arts Program was founded. While the program was not intended to function as a form of therapy, we all recognized the therapeutic undercurrent, value and potential of artistic and creative activity within hospital spaces. Since its inception, the program has enriched the experience of children, guest artists and medical staff on many levels. Furthermore, it has proven influential, at least for me, as it has shaped the philosophical foundation that informs my on-going work as an artist, educator and researcher concerned with creativity and the experience of well-being. I am therefore deeply grateful to Denis Daneman, Marcia Frank and Ana Artiles-Sisk, a nurse-educator at the hospital, who have contributed to my growth as an educator and researcher through their example.

Similarly, Anne Powell and Dora Bailey at Senior People’s Resources in North Toronto (SPRINT) embraced the goals of my academic work, providing me with on-
going support and mentorship throughout the process of my work with members of the adult day care program with Alzheimer’s. Above all, these individuals who have responded so warmly and positively to my weekly invitation to paint must be acknowledged. Without their contribution and collaboration this arts-informed research study would not have come to fruition. I acknowledge the persistence, courage and spirit of all my participants who enlivened the creative process and brought to life new ways of considering the potential of individuals with Alzheimer’s disease to actively learn. I must recognize my supervisors, Gary Knowles and Ardra Cole, for their commitment and encouragement throughout this life-altering and profoundly fulfilling process. Finally, I thank my family, Zoe, Sasha and Andrew, for their support, encouragement and love. Thank you all.
Table of Contents

Abstract .................................................................................................................. ii
Acknowledgements ............................................................................................ iii
Introduction .......................................................................................................... 1
Prologue ................................................................................................................ 3
    Self and Other .................................................................................................. 3
Chapter 1 Beginning the Journey ....................................................................... 7
    Awakening ..................................................................................................... 7
    First Steps .................................................................................................... 8
    The Participants ............................................................................................ 12
Chapter 2 Research Overview .......................................................................... 24
    Multiple Roles .............................................................................................. 24
    Methodology ................................................................................................. 26
    Phenomenology ............................................................................................. 31
    Feminist Post-structural and Anti-Oppression Theory .................................... 33
Chapter 3 Reframing Alzheimer’s ...................................................................... 45
Chapter 4 Student-Teacher Dynamics: Recognizing the Self in the Other .......... 57
    Inter-Subjectivity .......................................................................................... 57
    Mutuality ....................................................................................................... 64
    Reciprocity ..................................................................................................... 65
    The Gift of Presence: A Gateway to Reciprocity ........................................... 70
Chapter 5 Moving Toward the Moment ............................................................... 72
    Attuning ........................................................................................................ 72
Chapter 6 Learning Theory ................................................................................ 78
    Supporting Identity and Personhood through Learning ..................................... 78
    Learning Realms ............................................................................................ 79
    Montessori ...................................................................................................... 79
    Embodied Knowing ....................................................................................... 81
    Developmental Learning Theory: Piaget, Vygotsky and Rogers ......................... 83
    Adult Learning Theory .................................................................................. 85
    Intersections .................................................................................................. 85
    Teaching People with Alzheimer’s Disease: Therapeutic Education .................. 87
    The Third-Age ............................................................................................... 89
Chapter 7 Teacher as Caregiver ......................................................................... 90
    Reconcieving the Patient as a Person ............................................................ 90
    Person-Centred Care ..................................................................................... 91
    Mature Care .................................................................................................. 93
    A Case for Education .................................................................................... 94
Chapter 8 A Table for Four ............................................................................... 96
    Establishing the Research Locus ................................................................. 96
    The Program ................................................................................................. 97
    The Process ................................................................................................... 98
    Arts-Based Methods of Teaching Adults with Alzheimer’s ............................... 100
    Sharing as a Claim to Personhood .................................................................. 102
Qualities of Art.........................................................................................104
Chapter 9 Reflections................................................................................106
  Relying Upon Others for Care .................................................................107
  Need for Innovative Educational Programs ...........................................108
  The Essence of the work and future direction........................................109
References.................................................................................................114
Figures

Figure 1. The Haar. Painted by Kathleen Downie, acrylic on canvas (2008). 35cmx22cm (photographed by K. Downie) ......................................................................................... 6

Figure 2. Two Voices. Painted by Emma and myself (2010). Watercolour on paper, 35cmx22cm. (photographed by K. Downie) ................................................................. 11

Figure 3. Lowell (photographed by K. Downie, 2010) ............................................................... 13

Figure 4. Untitled. Painted by Lowell (2011). Watercolour on paper, 35cmx22cm. (photographed by K. Downie) ......................................................................................... 14

Figure 5. Sheila (photographed by K. Downie, 2010). ............................................................... 16

Figure 6. Theresa (photographed by K. Downie, 2010) ............................................................ 17

Figure 7. Theresa (photographed by K. Downie, 2010) ............................................................ 18

Figure 8. Betty Anne (photographed by K. Downie, 2010) ...................................................... 19

Figure 9. Betty Anne (photographed by K. Downie, 2010) ...................................................... 20

Figure 10. Rolande (photographed by K. Downie, 2010) .......................................................... 21

Figure 11. Untitled. Painted by Rolande (2011). Watercolour on paper using wet on wet technique, 35cmx22cm. (photographed by K. Downie) ........................................ 22

Figure 12. Lowell proudly shares his work with others who attend the adult day care program. (photographed by K. Downie) ........................................................................... 61

Figure 13. Reciprocal Learner-Teacher Model (created by Kathleen Downie and Jennifer Polo) .............................................................................................................. 69

Figure 14. Prepared working space. (photographed by K. Downie) .......................................... 99

Figure 15. Rooster and flame. Painted by Lowell. (photographed by K. Downie) .... 112

Figure 16. Lowell (photographed by K. Downie) .................................................................... 113

Tables

Table 1 Participant Continuum ............................................................................................... 15

Appendices

Appendix A The Neurobiology of Alzheimer’s Disease ......................................................... 119
Appendix B Differentiating Art and Craft ............................................................................ 121
Introduction

This thesis aims to inform educators directly involved in the training of caregivers, personal support workers and other frontline staff who facilitate educational and recreational programs for the elderly, specifically those with Alzheimer’s disease and related forms of dementia. Each of the chapters within this work examines and addresses aspects of the process of envisioning, developing and implementing creative, educational programs for people with dementia. This work reveals the stages of my personal process of discovery within the world of Alzheimer’s. It discusses the complex intersection of professional roles that inform arts-based education within arts-in-health programs; issues that impact care of the elderly; educational theory; and an overview of the process used throughout the 12-week study reported on in this thesis. An overarchingly assumption within this work is the belief that access to choices that support affirmative and active roles for people living with Alzheimer’s fosters communication, supports concepts of identity, and bolsters feelings of wellbeing. As well, this work views educational programs for people with Alzheimer’s disease as an integral aspect of care.

The title of this thesis, *On Reciprocity: Teaching and Learning with People who have Alzheimer’s*, draws the reader’s attention to the inter-connected and collaborative nature of teaching and learning. Indeed, reciprocity activates and enhances their interchangeability. Through mutuality the teacher becomes the learner,
and the learner becomes the teacher. Each person within this exchange is permitted the opportunity to lead and to be guided. This premise is foundational to the work that was accomplished at the SPRINT adult day care program. Together, we established a foundation of mutual trust, which enabled us to work as equals. This permitted recognition of new ways to engage, communicate and overcome challenges encountered within teaching and learning contexts. Out of this creative process a rich body of knowledge emerged.
Prologue

Self and Other

Self

The recognition of places within the self that are shaped by silence is a profound and compelling awakening because silence longs to be heard. The thought that such a human experience is universal brings to mind a cacophony of other silences emerging out of some form of oppression – whether political, emotional or physical. My own islands of silence, which I am becoming more familiar with, impose a tangible sense of isolation and discomfort. Thus, I am compelled to bring expression to the silence through my teaching, creative work and research, and to connect with others who struggle in a similar way. It was this awareness that guided me toward the silence that affects people with Alzheimer’s disease and other forms of dementia.

As a visual artist, teacher and researcher whose imperative it is to communicate in broad and diverse ways through visual, metaphorical and literal languages, I embarked upon a journey of self-actualization. This led me to graduate studies in adult education, which included the study of adult learning theory, theories of ageing and neurobiology. However, it was not until I arranged a practicum placement at an adult day care program that I truly began to learn about Alzheimer’s disease and its manifestations from the perspective of an artist-teacher-caregiver.

Other

Over the past year and a half I have come to know many people with Alzheimer’s disease and have shared with them a remarkable closeness defined by mutual presence
and respect. While verbal language is not always reliable, communication occurs on many other levels that transcend the spoken word. At other times, lucid, cogent words reveal clarity of mind in persons with dementia. When there is a loss of words, it is as if mind and heart, connected by a network of fine and colourful threads, become entangled and knotted in the location of voice. The great conductor of the mind reverts to slow deliberation as it searches for meaning and expression. At these times, the person with dementia appears to relinquish the hope of grasping the thought and acquiesces with grace saying, “it will come to me later.” It has become clear to me that those with Alzheimer’s dementia continually strive to adapt, connect and make sense of their world, while, at times, engulfed in what seems a fog. The mind also speaks through the heart, the eyes and through the wisdom of the hands that give and receive touch. To witness even brief moments of presence in a person with dementia is to verify their claim to the world which states in no uncertain terms, “I am here!” This is undoubtedly significant and important, as we may affirm the essence and voice of the person through our witness.

Between self and other exists a dynamic and sacred space\(^1\) that holds affirmation and the potential of transformational ways of being. Similarly, the haar – a thick and encompassing fog peculiar to Scotland – descends to obscure that which is visible, while delivering a mystical yet tangible presence. This phenomenon, portrayed in The Haar (Figure 2), brings to mind the manifestation and emergence of defining experiences co-created, enacted and embodied between two individuals. This image is noteworthy

\(^1\) (O’Donohue, 2008).
because I painted it shortly after meeting Helen Stirling at a nursing home in Scotland.

The space that emerged between us in our brief meeting was defining for me, as it was the first step in my journey toward re-conceiving notions of self and other.
Figure 1. *The Haar*. Painted by Kathleen Downie, acrylic on canvas (2008). 35cmx22cm (photographed by K. Downie).
Chapter 1
Beginning the Journey

Painting The Haar, after my return to Canada, became an act of perceiving something within myself that longed for recognition. I understood this as I completed the image, revealing pleasing and subtle marks upon the canvas. What I did not understand at the time was that this image signified an important aspect of my future. Through the expression of this artwork, my unconscious mind envisioned and formulated things that I was not yet ready to consciously understand. The image, restful and beautiful, offered its invitation.

Awakening

Presence of mind may emerge and grow through creative action, meditation, prayer, physical activity, rest, or perhaps even crisis. Helen Stirling was my awakening to a presence that was vaguely familiar, yet unnamed. She was an older cousin of my partner Andrew and whom we met in St. Andrew’s on a trip to Scotland. Then 65, she had lived with frontotemporal dementia for over a decade and had recently been moved to a nursing home. Standing neatly dressed, with purse in hand, Helen waited at the end of the corridor for our arrival. She greeted us warmly as we approached, gave Andrew a big hug, and then guided us back to her room. There we sat and chatted about her family and husband, whom we had just visited at their home in the nearby village of Crail. Her memory of the distant past was quite remarkable. In response to our questions about her family pictured in a large portrait hanging on the wall, she recalled and named each person. She spoke of her time in Toronto where she worked as a radiographer at the Hospital for the Sick Children in 1967, and traded stories with Andrew about their ancestors. However, her short term and working memory presented many problems. She could no longer read or write and conversation that relied
upon the exchange of thoughts in the moment prompted her to mirror our words back to us. This sophisticated strategy must certainly have buttressed her sense of dignity, while enabling her to carry our conversation forward. While she accomplished this effectively, the appearance of strain grew in her eyes as we spoke. I became attuned to her anxiety and took her hand, as if to reassure her in some way. In those brief moments I felt a powerful connection with her that enabled us to speak in our silent way, through the meeting of our eyes and the touch of our hands. This was beginning of a promising journey.

First Steps

The brief yet profound meeting that I shared with Helen in Scotland led me to pursue graduate studies in Adult Education at the Ontario Institute for Studies in Education (OISE) at University of Toronto. It was through the process of determining a practicum placement for the final course of a Masters degree that I came to learn about SPRINT\(^2\). This agency provides a range of community support services for seniors, which include meals on wheels, in-home personal care, transportation services and respite care. The adult day care program is a respite service that offers stimulating social programs and nourishing hot meals for its elderly members, many of whom have Alzheimer’s disease and related forms of dementia. This placement enabled me to gain both hands-on working experience and a location to conduct fieldwork in advance of my proposed study on learning in Alzheimer’s.

During this time, I established a close bond with one of the day program members who, much like Helen, guided me in my learning of attunement and subtle modes of communication. Though Emma (a pseudonym) was not a formal participant of the later

\(^2\) Senior People's Resources in North Toronto, was mentioned earlier in the Prologue. It will be referred to as SPRINT from this point onward.
study, our collaborative work informed the development of the research that followed several months later. Emma was the youngest adult day care program member. Our shared Irish lineage and closeness in age most certainly contributed to our connection. In her early sixties Emma was already in the late mid-stage of early-onset Alzheimer’s. A form of aphasia further complicated her dementia causing her to jumble the sequence of her words as she spoke. As such, it was quite difficult to understand her spirited conversation. As she retained insight into her state, she appeared frightened and teary at times. Eventually, she became so consistently frustrated and agitated that her family had to withdraw her from the program. However, before this eventuality, the work that we engaged upon together permitted joyful and creative interludes, which affirmed the benefits and potential of arts-based educational programming for people with dementia.

Emma and I painted together frequently. Sometimes conversing and at other time in silence, we conjointly immersed ourselves in the joyful, fluid process of painting. Often, the physical act of painting can loosen the tongue, opening new pathways in the brain that prompt conversation. And so it was during these moments that I came to know Emma as a sharp-witted woman who appreciated irony, loved her children dearly and still felt the pinch of angst that teenagers arouse in their parents. She was so humorous, often igniting contagious bouts of laughter among all in her midst. The close bond that Emma and I shared became visualized in one of the paintings that we created together (see Figure 2). Two, sweeping blue arcs converge within the centre of the picture plane. The merger of the curved lines, a watery reflection within a dreamy landscape, may well represent the sense of collaboration that we enjoyed together. The curves also seemed to refer to aspects of Emma
herself. When she spoke, Emma often referred to a woman around the “curve”, upstairs or around the corner. My sense was that she was speaking about an obscured aspect of herself, a woman who existed within another realm of herself. Curved lines and shapes became one of the hallmarks of her artwork.

As her disease progressed, she became more agitated and difficult to settle after her arrival at the centre in the morning. One day, a day when I was not at the centre, the staff exhausted every strategy that they knew to contain Emma’s anxiety and help her settle into the program. Finally, one of the caregivers said, “Let’s do what Kathleen does.” She took out the paints, brushes and paper and Emma suddenly became calm. She sat down with the caregiver and began to paint. She was restored. Hearing the story later that week, I felt a deep sense of satisfaction. The work, which I knew in my heart-of-hearts was important, became validated. The preliminary work accomplished with Emma and others during this period of field-work, established the groundwork for what finally evolved as a formal research study.

---

3 The presence of the art supplies triggered an embodied memory of the experience of painting within a caring and social context. In this way, the emotional and sensory experience of painting was evocative and full of memory.
Figure 2. Two Voices. Painted by Emma and myself (2010). Watercolour on paper, 35cmx22cm. (photographed by K. Downie).
**The Participants**

The aim of this 12-week art program was to facilitate communication and expression in people with Alzheimer’s through the use of visual arts media, and to examine the emergence of learning phenomena at procedural, cognitive and affective levels of experience. The participants provided consent and were informed that their involvement in each session was invitational. This allowed each person to accept or decline participation in the program at the beginning of each session. Through the establishment of a safe, failure-free and invitational framework, those in the group demonstrated an overall willingness to participate in the activities each week. The relational benefits of the program became apparent when the participants eagerly expressed a desire to continue, as they anticipated upcoming sessions.

Of the 10 participants, five emerged as outstanding in terms of their interest and engagement in the learning process. Furthermore, their ongoing and continued commitment to the painting sessions, and their level of satisfaction surpassed that of others whose interest demonstrated a gradual decline over the long-term. Most of the individuals in this emergent group still paint with me on a weekly basis. They continue to demonstrate growth and awareness of their ability and the things that they require\(^4\) in order to feel successful as learners. While the contribution of all of the participants is highly valued, I draw particular attention to Lowell, Sheila, Theresa, Betty-Anne and Rolande, whose work and processes are of central interest to this work.

As I observed and reflected upon the participants’ responses to the program, I recognized a continuum of reactions to the sessions as they progressed. These responses

---

\(^4\) This demonstrates evidence of metacognitive awareness, i.e. conceptualizing and understanding the self as a learner with specific needs.
range from Initial refusal to Shares and reflects upon own and other’s work. These observations are expressed in the Participant Continuum (see Table 1) chart.

Figure 3. Lowell (photographed by K. Downie, 2010).

Lowell is a tall and slender 77 year-old with a kind and vibrant face. His long silver ponytail, beads and other interesting pieces of jewellery that adorn his hats, hands and even his tote bag speak of another era that frames my birth and early years. He is a throwback, as some might say, though an original in my mind. He is one in whom social awareness and concern for others continues to exist. He embodies a youthful spirit, generosity and an outgoing nature. He was a professor of social work at the University of Colorado. Astute
and articulate, even when words seem lost, he gathers joy and purpose from each moment. Lowell’s “old-man” Alzheimer’s, as he calls it, has progressed quite rapidly since his diagnosis in recent years. Yet, he is vocal about his loss of memory, insightful and unafraid to speak of his experience.

Figure 4. *Untitled*. Painted by Lowell (2011). Watercolour on paper, 35cmx22cm. (photographed by K. Downie).
### Table 1

**Participant Continuum**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Initial refusal</th>
<th>Hesitant but joins class</th>
<th>Accepting of process</th>
<th>Rejects process</th>
<th>Willingness to try again</th>
<th>Questions &amp; asserts needs</th>
<th>Demonstrates adaptability</th>
<th>Expresses satisfaction</th>
<th>Expresses joy</th>
<th>Shares and reflects on own and other’s work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afia</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Betty-Anne</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Felix</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Francis</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helene</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joyce</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowell</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rolande</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sheila</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Theresa</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

15
Figure 5. Sheila (photographed by K. Downie, 2010).

Sheila is a 90 year-old who appears much younger than her years. She is outgoing and enjoys the company of others, often expressing her gratitude for life and love of learning. She takes great pride in the artworks that she creates, although at times she is self-deprecating and responds well to encouragement. Despite this tendency, she views herself as a learner whose ability to paint is improving. Sheila’s lapses of memory are associated with an early-stage Alzheimer’s-type dementia. She is able to
focus well on her work for extended periods of time without assistance and make executive decisions.

Figure 6. Theresa (photographed by K. Downie, 2010).

At the age of 92, Theresa defies her age. She is a stylish, petite and spirited woman of Italian descent who enjoys life to the fullest. Theresa has Alzheimer’s-type, vascular dementia and lives in relative independence with her daughter in the home that her husband built shortly after their marriage sixty years ago. She is spritely and kind natured, always eager to paint and share stories of her family. Theresa loves painting and easily delves into her imagination, the source of her imagery, which continues to inform her creation of whimsical landscapes. These are steadily becoming more complex and accomplished.
Figure 7. Theresa (photographed by K. Downie, 2010).
Betty-Anne, in her late 70s, lives in an assisted living residence for people with Alzheimer’s. In the early stage of Alzheimer’s, she is equipped to live quite independently, while having support services close at hand. She was somewhat reluctant to participate in the art classes initially. However, she quickly gained confidence in her ability to paint once she became more familiar with the group and our process. Over time she became more accepting of her unique and distinctive painting style and willing to accept her stylistic tendency. While she did not continue to paint with the group after the conclusion of the study, she progressed through each stage of
the continuum (see Table 1), to achieve a strong sense of accomplishment and pride in her work.

![Betty Anne painting](image)

**Figure 9. Betty Anne (photographed by K. Downie, 2010).**

Betty Anne’s style was very reflective of the manner in which she painted. She often used short, linear brushstrokes that moved across the paper on the diagonal. She was discouraged to see that she always did the same thing. When she said this, I drew her attention to her choice of colours which were always bright and harmonious. I then described her paintings as “raining joy.” This pleased her greatly and helped her to accept her tendency as a pleasing painterly style. Furthermore, she began to see the beauty of her work.
At the age of 83, Rolande is in the most progressed state of Alzheimer’s. While French is her first language, she has primarily been an English speaker, who in recent months has reverted to speaking French. When we first met, Rolande’s vocabulary was restricted to the word yes, which she enunciated in a drawn-out fashion saying, “yeees.” After several sessions of painting she began to speak more, and with greater fluency, employing a greater lexicon of words and phrases. Throughout the study she made great
progress. In addition to her improved verbal expression, she was also able to follow simple directions and work with increased independence as she worked. Rolande’s occasional placement in an overnight respite care program interrupted her attendance at the day program. While this appeared to impact her willingness and ability to paint, when she returned to the program at SPRINT she was able to re-establish her ease of fluency. Rolande, much like Emma, continues to respond positively to the sight of the painting materials and demonstrates an ability to follow simple directions and complete several small paintings during each hour-long class.

![Figure 11. Untitled. Painted by Rolande (2011). Watercolour on paper using wet on wet technique, 35cmx22cm. (photographed by K. Downie).](image-url)
For each of the participants shown here, the painting process was embarked upon in the spirit of trust and discovery. Ensuring that each participant had a familiar and consistent space at the table equipped with their own set of art supplies (see Figure 14), contributed to an overall experience of continuity and safety. Spending time with each individual at the start of the session helped to establish trust, which enabled feelings of confidence and acceptance. These simple steps served the interests of all and contributed to the collaborative and social nature of our meetings.

Conducting an arts-informed research study, such as this, requires flexibility, patience and finesse all of which enable the experience of satisfaction for all. While the imperatives of the researcher are also crucial, these must be relinquished at times in favour of the integrity and well-being of each participant. This is one way in which the researcher, informed by multiple competencies, draws upon their experience to meet the imperatives of both the research process and that of the participants. As this research was both educational and arts-based, the roles of educator and artist well complemented the researcher role.
Chapter 2
Research Overview

Multiple Roles

Examining the potential of new learning in people with Alzheimer’s disease requires an open-ended and inductive research approach. This is because learning in people with Alzheimer’s must be broadly and generously conceived due to the nature of the disease. This does not mean that concepts of learning should be ‘watered down.’ Rather, they should be constructed to recognize and value the subtle and unique expressions of each individual learner in broad and holistic terms. This work stems from artful methods of teaching that facilitate learning in multiple ways. Creative and artistic forms of expression are used to support communication and expression, which in turn reflect deeply held notions of identity. To this construction is added the perception of self as a learner.5 The principles of adult education combined with those of arts-based education further compliment and extend the rich purpose of arts-informed research methods to explore, interpret and articulate ideas in diverse and accessible ways.

Thus arts-informed research draws upon multi- and inter-disciplinary skills that are intrinsic to the researcher. In this case, I am an educator, artist and academic concerned with the intersection of communication and quality of life, generally speaking, and in particular to people with Alzheimer’s disease. Aligned with these roles and concerns are educational theories, artistic methods, epistemologies and philosophies that inform, guide and drive the research process. Through each role the artist, educator,

---

5 (Bromme, 2010; Kolb, 1983).
and researcher interprets and influences other aspects embodied within this triad to complement and challenge the process.

The primary role of the educator is to approach the adult learner as an equal, while recognizing the individual’s proficiencies, personal and professional expertise and broad life experience. From this perspective the educator divines the talents of the learner, to support and facilitate new learning within creative spaces, within a close-knit learning circle or the community at large. The artist invites open-ended exploration, experimentation and discussion, while utilizing available materials and resources, to reveal new ground and avenues of exploration.

The influence of the educator role upon that of the artist is important, as the educator who listens and observes well, reminds the artist to relinquish his or her aesthetic purpose and personal need in favour of the goals of the learner. This can be a significant challenge for artist-teachers who may desire to place the production of a satisfying product before that of a process-oriented experience.

Added to this dynamic is the arts-informed researcher who utilizes observation and analytical skill to balance a vision of potential outcomes with opportunities, often unpredictable, that emerge out of an ever changing creative process. These opportunities are manifest through the phenomena of the moment, which call for a thoughtful response. Thus the educator as diviner, the artist as conduit, and the researcher as witness, each contribute to a rich and dynamic process of discovery.
**Methodology**

Arts-informed research is a form of qualitative research based in the social sciences, infused by the arts\(^6\) and artistic processes. It is an innovative, open-ended, transformational and evocative methodology, which rejects positivist notions of a singular truth and claims to authority.\(^7\) Rather, arts-informed research draws attention to the viability of multiple truths and different ways of knowing,\(^8\) permitting broad audiences access to and intercourse with engaging, rigorous, scholarly work that reflects the evolving nature and iterative quality of knowledge as creative force. Its central purpose is to enhance understanding of the human condition\(^9\) through discourses that invite those within the public sphere to engage and interact with scholarly works interpreted through artistic representation.

The elements of arts-informed research are broad and complex in their consideration of academic rigor and the open process of inquiry engaged upon through artistic work. Arts-informed research is therefore firmly rooted in scholarly method, guided by postpositivist theory and informed by the arts – music, dance, theatre, creative writing and the visual arts. The defining elements of arts-informed research are:

1. *Commitment to form*: the art form ultimately embodies the research text\(^{10}\) thus it is the armature that defines and directs the inquiry process and shapes

---

\(^6\) (Cole, 2007).
\(^7\) (Cole, 2007).
\(^8\) Patti Lather speaks of diffusing the power of the author to make knowledge accessible and improve the “democracy” of knowledge.
\(^9\) (Cole, 2007).
\(^{10}\) (Cole, 2007).
the emergent text. Form is a serious consideration that the researcher must attend and respond to throughout the research process.

2. **Methodological integrity**: the chosen art form must be relevant and reflect the nature and needs of the research. In the case of my current research study, the fluid character of watercolour paints lends itself to the notion of flowing imagery. Likened to the flow of words and the creation of visual languages, the art form becomes an alternative mode for the expression of thoughts, ideas and feelings in people with dementia.

3. **Creative inquiry**: the researcher lends herself to an often unpredictable and fluid creative process, which requires both conscious and effortful attempts to direct the flow of creative activity, and the relinquishment of conscious effort to assume a sort of blindness that relies upon intuition as its guide. While this may sound like a free pass, the creative process is a risky endeavour, as it tends to defy established structures. This is the strength of creative inquiry, not limited to arts-informed research, because it seeks to establish alternative paths and new ways of seeing the familiar. The notion of neuroplasticity, as discussed by Doidge (2007), demonstrates this principle beautifully. He describes established neural pathways in the brain, which fire sequentially in response to commands, as analogous to ski runs in the snow. In order to create new neural pathways, the brain needs to look at problems in new ways using conscious effort. This effortful and deliberate work engages different sets of neurons that fire together to become linked. It is said that neurons that

---

11 (Doidge, 2007).
fire together, wire together. Doidge (2007) likens this rewiring to skiing on freshly fallen snow. With each new ski run, the skier's path becomes more deeply entrenched in the track of snow. This presents advantages as disadvantages – permitting ease on the one hand and resistance on the other. Breaking free from the path presents new options on the piste, yet the tendency to stick with the tried and true is ever present. This analogy represents the paradox of neuroplasticity,\textsuperscript{12} which affords constant opportunities to create new neural pathways, while at once tending toward the convenience of the known. Likewise, the arts-informed researcher must be wary of the tendency to practice that which works in predictable ways and remain open to innovation. The inductive process of creative inquiry demands of the researcher an ability to work within established frameworks, while dismantling these structures using foresight, insight and flexibility. In this way the arts-informed research process becomes expansive and full of possibilities.

4. Presence of the Researcher: the researcher positions herself at the centre of the work, to experience the flow of events from the dual perspectives of insider and outsider\textsuperscript{13}. As such, the notion of objectivity is questioned and suspended, allowing the researcher to simultaneously engage and disengage throughout the research process as both subjective participant and objective witness. Here, the researcher must consider and clearly define the multiple roles that she assumes in this process. In my case, I am an educator-artist-

\textsuperscript{12} (Doidge, 2007).
\textsuperscript{13} (Gallagher, 2009).
researcher who at once facilitates, participates in unison with each participant, and observes the process. Understanding these separate roles enables me to transition between each identity effectively. While multiple researcher-roles present challenges, they allow for the development of empathy and a deep sense of knowing. The researcher positioned within the centre of the work must also claim the personal “I,”14 thus identifying personal sources of connection and motivation, which drive the process while emphasizing the “provisional and partial grounding of claims”15 inherent in the work. These qualities are essential to and congruent with research that is concerned with people with dementia, because claims to knowing within the caring context are questionable, and must always give way to empathic modes of being, sharing and communicating.

5. Reflexivity: the researcher must actively practice reflection as a mode of distilling the themes and ideas that emerge through the creative research process. This reflexive practice develops out of an awareness of conscious and unconscious streams of thought and subtle responses to the work in progress. Reflexivity corresponds to flexibility and attunement to the work of the research participants and emergent phenomena.

6. Audience: arts-informed research intends to elevate consciousness, expand awareness and knowledge, and influence learning among broad and varied audiences. The researcher must hold this in mind, as she works to gather and

14 (De Freitas, 2007).
15 (De Freitas, 2007).
represent the data in a dynamic and engaging way, so as to invite the audience to enter the work. Through this *entering*, the viewer becomes informed and transformed by the sensory experience conveyed through the artwork that embodies the data interpreted and represented by the researcher.

7. *Audience engagement*: through audience engagement the representation of data is once again transformed much like the iterative process of printmaking, which relies upon a variety of techniques to alter the print image. For example a lithograph may be reproduced through photography, then again though a photocopy, then again through anagram transfer. Though originating from the same original artwork, each subsequent print is transformed, revealing new facets within the image. Similarly, audience response to *The Alzheimer’s Project*,\(^{16}\) written by caregivers sharing their experiences of caring for a person with Alzheimer’s disease, culminated in the creation of a second arts-informed research piece entitled *Love Stories*,\(^{17}\) a recorded compilation of narratives about caregiving as the enactment of love.

These elements establish a groundwork that serves as a guide for the researcher informed by multiple- and inter-disciplinary practices working within the field of education. While learning has been conceptualized and defined through the developmental theories of Piaget, Vygotsky, Erikson and Rogers, it is a complex affair influenced and determined by the unique cultural frameworks and experiences of the

\(^{16}\) (Cole &McIntyre, 2004).

\(^{17}\) (Cole &McIntyre, 2004).
learner across their life span. Arts-informed research, multi-disciplinary in nature, coheres with the complexities of learning and communicating. The theories that define psychological development, particularly those of Vygotsky and Erikson, point to the fragile and tentative nature of language – the very cornerstone of culture, knowledge and meaning – toward the need to recognize and develop non-linear modes of communication found within artistic expression.

*Phenomenology*

The phenomenological perspective at once embraces and is embraced by the artist’s way. It is an essential aspect of arts-informed methods, which explore and interpret through the creative impulse and all that this entails. Creativity is a process of interpretation that works through the artist who perceives, distils and represents ideas of concern in multiple artistic ways. An artist, whether a musician, painter or sculptor ponders their subject and grapples with its nature, so as to forge a representation of the truth as perceived by the artist. Similarly, “phenomenology attempts to distinguish what is unique.”

It looks beyond assumptions, while paying close attention to detail and the subtle qualities bound within the essence of the moment. Awakening to these qualities requires a level of disciplined practice that brings about stillness and a quieting of the mind. In this way, it becomes possible to recognize that which is otherwise obscured from view. Fleeting moments, like miniscule fragments of matter, are beyond comprehension. Yet moments in time exist as minute and enormous all at once – inconceivable. Resolving this confounding paradox is consuming, and must give way to the aesthetic of the moment which, given time, reveals new facets of experience.

---

18 (Van Manen, 2005, p. 85).
Van Manen (2005) identifies this as recognizing the “difference in sameness.”\(^{19}\) Through the act of paying attention, attending to the fine subtleties of the ordinary everyday world, we may begin to experience the extraordinary. Attentiveness, intimacy (i.e., the personal) and empathy help us to attune to the moment and to the experience of others. By stilling the often-overwhelming distraction of the outer and inner worlds of existence, it becomes possible to view our lives in new ways. Interestingly, people with Alzheimer’s are adept at focusing and connecting with others within the focus of the fragile and dynamic moment. This is because they are deprived of the memory of the immediate past.\(^{20}\) The gradual quieting of the mind resulting from Alzheimer’s brings about states of focus and mindfulness. To be in close proximity with such a person allows others, oriented toward stillness and reflection, to bathe in the slowing of time.

This phenomenological essence lends much to the discussion of the elderly and ways in which old people are perceived and treated within contemporary society. Applying a phenomenological paradigm to an arts-informed study aimed at exploring learning phenomena in people with Alzheimer’s is appropriate and essential to considering alternative views of people with Alzheimer’s. Engaging with others, as well as ourselves, in mindful and gentle ways, permits entry into new possibilities within our relationships, particularly with those who are marginalized or otherwise vulnerable. In seeking to reveal and interpret newness within the ever-changing landscape of personal experience, our view of the world and others becomes transformed.

\(^{19}\) (Van Manen, 2005, p. 86).

\(^{20}\) Memory loss varies among individuals throughout the stages of the disease.
While a phenomenological, arts-informed methodology informs the manner, action and process of this research, a post-structural feminist epistemology further broadens the scope of potential frameworks through which to view the elderly, particularly those with dementia, in a bid to improve their quality of life.

**Feminist Post-structural and Anti-Oppression Theory**

Arts-informed research methodologies are by nature open-ended, inductive and multi-dimensional in their approach, interpretation and representation. Aligning method and theory is an essential marriage of values and qualities that sustains the research process in an engaging, informative and challenging way for both the researcher and participants. The consideration of learning potential in elderly people affected by Alzheimer’s dementia immediately brings to mind many problematic questions. Is it possible for a person with a neurodegenerative disease to learn? If so, how is learning defined? How do notions of dementia shape and challenge education? How and where should educational programs for people with Alzheimer’s be implemented and by whom?

In order to respond to these questions and others within this tentative and problematic terrain, the methodological and theoretical foundation considers and challenges established, if not entrenched, beliefs about ageing, neurodegenerative disease and notions of learning in people with Alzheimer’s. Feminist post-structural theory lends an impassioned and compassionate voice to discourses concerned with access to knowledge and power, expressing its concern about social imperatives that marginalize those among the weakest in society. In challenging hegemonies that claim
both rightful and righteous knowledge of the body, mind and behaviours, others may claim for themselves opportunities to express their voices in vibrant and meaningful ways.

The consideration of four foundational elements of feminist post-structural theory – uncertainty, deconstruction, bodily knowledge and rethinking power, as outlined by Todd and Burns (Todd, 2007), shines a light upon the discussion of ideas related to the potential of people with Alzheimer’s to learn and affirm their knowledge. Through the lens of these elements, the reader of feminist post-structuralism may recognize new possibilities and opportunities that recognize those living with Alzheimer’s as adaptive and continual learners.

Uncertainty: uncertainty accompanies life itself and longevity raises many prospects and complexities for the elderly related to health and emotional and financial security. The way in which we “make meaning of ourselves, our interactions, and the world around us”21 relies upon reflexivity and sensitivity towards the needs of others.

Deconstruction: through an analysis of the systems that determine and shape the function of society, we begin to recognize ways in which some things are made possible while others are precluded.22 Education is a primary construct of society which is highly political and inexorably tied to economic imperatives. Deconstructing these systems facilitates new perspectives.

---

**Bodily Knowledge:** bodily knowledge is contentious and mysterious. Post-structural analysis allows us to question the notions of ownership and power over one’s own body. As well, it points to Descartes’ conceptual division of the mind and body, which confounds the relationship between the rational and emotional aspects of being. Disembodying the self (as identity) from its capacity to act within the world truncates personal function and influence in the world.

**Re-thinking power:** in its inherent self-interest, power relations neglect to address inclusive and open communication. Post-structuralism lends itself to the voices of many, in an attempt to achieve balance and collaboration for a broader social good.

Central to feminist post-structuralism is the consideration of ways in which power relations are sustained “through a complex network of seemingly natural interactions, presences, and absences.” Indeed, ideas and behaviours that often appear naturally ordained rise out of beliefs and practices that accord power or privilege to one group over another. Feminist ideologies have long challenged notions about the natural role of women in society. In more recent years feminist theory has facilitated discourses about contentious issues related to notions of gender and family. Conceiving of alternative and inclusive ways of being, the family is continually transformed to adapt to the needs and desires of broad social groups. There are multiple ways of experiencing the social interaction of family life, and many ways to contribute to a caring and diverse community.

---

23 (Derrida, 1990, 1994, as cited in Todd, 2007, p. 26)
Similarly, post-structural feminist ideologies lend new perspectives and inform discourses about ageing, sexuality, lifestyle and wellbeing for the current cohort of Baby Boomers identified as the Third-Age. True to its postmodern origins, post-structural theory acknowledges its limitations and the uncertainty of solving complex problems in singular ways. Furthermore, reflexive, dialogic and relational approaches are important to the consideration of issues that affect individuals and groups within their social milieu.\footnote{(Todd, 2007).}

In keeping with Freire (2000), dialogue is not a means to an end but rather an invitational process that brings about an exchange of ideas that facilitate meaningful change at political and social levels.\footnote{(Macedo, as discussed in Friere, 2000).} Indeed, within the scope of this thesis the personal is political, particularly as concerns political and social perspectives that shape and determine the lives of the elderly. Seeking alternative structures that emancipate and expand human options and potential within society is served by the transformative and revolutionary ideas of Gramsci and Friere (2000), each of whom confronted and challenged the political hegemony of their time to empower and liberate the hearts and minds of the oppressed masses. Coupled with political oppression is the subtle oppression of language that attributes characteristics and qualities that determine worth and define identity in negative or limiting terms.

The element of deconstruction within post-structuralism considers the power of language and its impact upon individual and collective perceptions and agency. For
example, studies in languaging\textsuperscript{26} demonstrate that elderly people living in relative isolation in residential care homes respond positively, emotionally and cognitively, to relevant and interesting conversation. Participants in Swain’s (2010) study demonstrated a desire to continue socializing in this manner after having positive and affirming social experiences. These interactions contributed to improved self-esteem. This contrasts sharply with languaging that infantilizes and diminishes the agency of elderly persons, particularly those with disabilities. Through theoretical discourses that deconstruct language, it is possible to become sensitized to the power inequalities presented by messages embodied within our communication of language,\textsuperscript{27} through words, tone and gesture.

The embodiment of knowledge is another principle ensconced within post-structural theory that informs and responds to the scope of this study. “Post-structural approaches enrich a structural foundation in that they provide the space for us to consider the powerful ways in which our emotions and bodily experiences of emotions shape our practice.”\textsuperscript{28}

Post-structural feminist theory and anti-oppression theory cohere through their ambition to redress structural issues – the political, social and economic mechanisms – that shape and determine human existence and facilitate the marginalization of individuals through classist, racist, heterosexist and ageist beliefs\textsuperscript{29}. Furthermore, these

\textsuperscript{26} (Swain, 2010).
\textsuperscript{27} (Todd, 2007).
\textsuperscript{28} (Todd, 2007, p.).
\textsuperscript{29} (Todd, 2007).
theories emphasize the collective, inter-connected and sustainable aspects of social living over that of the self-determined individual. Together, these theories imagine new roles and ways of being for individuals living and working together in sustainable ways within complex and challenging social worlds.

In referring to Friere’s pedagogy of the oppressed (2000), I draw attention to the marginalization and double-oppression of the elderly who live with Alzheimer’s disease and other forms of neurological disease. The elderly are frequently omitted from full participation in social roles, as were women prior to and after World War Two. Economic, social, physical and cognitive losses further reduce the self-efficacy of elderly people. This growing cohort may parallel the masses of the impoverished underclass of Mexico for whom Freire (2000) sought empowerment through the notion of conscientização. As Freire’s revolutionary call to action radicalized the oppressed of his country, so too may detrimental perspectives of the elderly, specifically those living with neurological diseases such as Alzheimer’s, may be altered through radicalization. Social change fought for and delivered through educational theory restates and emphasizes the nature of learning as a social and transformative phenomenon that changes the individual who in turn continually responds to and reshapes the living social context. Through its recognition of reciprocal generativity post-structuralism speaks to dynamic, relational interactions that occur between the

---

30 (Friere, 1970).
31 Paulo Freire’s Pedagogy of the Oppressed continues to inform educational practice as a social and transformative pedagogy.
32 (Vygotsky, 1993; Piaget, 1972; Rogers, 1989).
33 (Hendricks & Hatch, as discussed in Bengston et al., 2009).
individual and society such that social imperatives act upon the individual who internalizes and reproduces “collective perspectives.” In this way, the actor and social world are not polarized; they are viewed as co-informants of their social world.

Post-structuralism endeavours to deconstruct deeply ingrained ideas that narrowly define social, cultural and political values and, coincidentally, ascribe bodies of knowledge to and acceptable roles within normative social, cultural and political frameworks. These exclusive and inaccessible institutions inherently resist change, contrary to those who seek to negotiate and distribute wealth, human resources and knowledge in more equitable and accessible ways. The weak and marginalized are easily constrained, even within a wealthy and prosperous nation such as Canada. Where housing, education and healthcare, all essential to wellbeing, might be viewed as political imperatives in a rational world, meeting the fiscal bottom line consistently overrides the hope of achieving improved quality of life for the weakest among us. Freire’s anti-oppression theory focuses upon disparities that arise between those who may access the privileges associated with power and those who may not, amidst social, political and economic mechanisms that fuel the ever-widening gap between poverty and prosperity.

Paulo Friere’s (2000) pedagogy aims to empower the learner as a vital social, cultural and political agent. Through knowledge of self and awareness of social systems and constructs of power, change is made. To enlighten those who are powerless is to enervate and radicalize the individual who becomes endowed with a deep moral

34 (Hendricks and Hatch in Bengston et al., 2009).
Indeed, it is necessary to challenge the dominant ideologies that encompass notions of learning and intelligence, since these beliefs have the power to distort identity, dehumanize and marginalize those who are vulnerable and easily exploited. “Dehumanization, which marks not only those whose humanity has been stolen, but also those who have stolen it, is a distortion of the vocation of becoming more fully human.” In this vein, Tara Fenwick challenges social and ideological constructs through her examination of adult learning and power relationships, questioning domains, institutional and otherwise, which “manage” notions of learning. Fenwick (2010) cautions that experiential, reflexive and “privatized” meaning making runs the risk of ignoring issues of “identity, politics, and discursive complexities of human experience.” Furthermore, she points to the importance of the nature of learning as “embodied, communal and fruitfully incoherent.” While Fenwick (2010) challenges the problematic inherent to Kolb’s notion of reflexive, experiential learning – concepts that are essential to this thesis – I recruit Fenwick’s (2010) notion of experiential learning, tempered by a critical awareness of social constructs, as an equalizing force that grounds this complex and sometimes tentative examination of learning in people with dementia.

---

35 (Freire, 1970).
36 (Freire, 1970).
37 (Fenwick, 2010).
38 (Fenwick, 2010).
39 (Fenwick, 2009).
40 (Fenwick, 2009, p.).
41 (Fenwick, 2000).
42 (Fenwick, 2009).
To accept the notion that a person with Alzheimer’s disease will be confined to a certain and prescribed demise within 10-15 years of diagnosis is to curtail the potential of the person to rise to the challenge of the disease and transform their life experience. By altering dominantly held notions of the disease, individuals with Alzheimer’s, their families and communities at large stand to gain opportunities for personal, social and political growth. However, claiming the role of continued learner for those with Alzheimer’s disease is highly problematic because it challenges many assumptions about the capacity of the mind affected by neurological disease. It also calls into question the very meaning of learning. Therefore, concepts of learning in people with Alzheimer’s are considered within, although not limited by, a context of therapeutic and rehabilitative learning programs that aim to bolster identity, self-esteem, communication, relationships and quality of life. Having stated this clearly, it is also possible to embark on learning programs that challenge the mind, captivate the imagination and build collaborative practices through which diverse ways of communication and understanding may be recognized and celebrated.

Essential to educational processes that are inclusive in their scope is an acceptance of the intrinsic personhood of those with Alzheimer’s and other communication disorders. While at once recognizing the mystery and power of the human mind and spirit, it is equally important to acknowledge the very real effects of Alzheimer’s upon the brain in people with the disease. Not only do amyloid protein plaques accumulate within the white matter of the brain, at a cellular level nerve cells become infiltrated by neurofibrillary tangles (NFTs) that hinder the nerve’s capacity to
carry messages from the tail of the nerve – the axon – to the synaptic spaces at the head of the nerve. A very complex neurochemical sequence is at play here, whereupon the shape and function of healthy brain cells are altered. While the sensory aspect of the nervous system remains intact, the mechanisms by which information is used to construct meaning and communicate ideas is grossly affected. Having stated this clearly, the brain is also remarkable, and the human spirit even more so.

Therefore in establishing spaces and learning opportunities for people with Alzheimer’s, educators must be informed and able to acknowledge both the neurobiological reality of the disease, as well as the remarkable potential of the human brain to sustain itself throughout the course of illness and disease, and in some cases, recover from neurological trauma. Indeed, while several notable writers have demonstrated the potential of the brain to recover from brain injuries once deemed hopeless through painstaking therapies which build new neural networks and pathways\textsuperscript{43} in the brain, one must ask how this knowledge might contribute to slowing the progression of neurodegenerative diseases through rigorous physical and mental activity.

The benefits of effortful cognitive work supported through the methods and principles of special education, and non-traditional arts-based educational methods may prove to be important breakthroughs in the long-term management of the progression of disease in people with Alzheimer’s. Broadening the meaning of what it is to learn permits opportunities for inclusion, enrichment and access to lifelong learning for people with dementia. The current debate about therapeutic education is one such example of

\textsuperscript{43} (Doidge, 2007).
this problematic. In this case, therapeutic education is a function of the affective domain of learning, which Ledux identifies as critical to neurobiological processes associated with memory and learning. While emotions aid and abet the brain’s chemistry, feelings are associated with the soft skills associated with the right-side of the brain. This theoretical stance challenges social constructs and perceptions about dementia, while examining three realms of potential learning within the unique experiences of people with Alzheimer’s who regularly attend art classes at an adult day program. Thus, this research draws together the complex realms of learning (both formal and informal) enacted within the specialized context of caregiving spaces. Using multiple theoretical layers rooted in feminist post-structural inquiry, this work overlaps and connects realms of education with modalities of care, drawing upon models of person-centred care and attuning.

Poststructuralist and anti-oppression frameworks are complementary in their advocacy of marginalized individuals and communities that confront cultural, social and economic hegemonies. Structures that maintain the status of deeply embedded social ‘norms,’ claim a passive false consciousness which fails to acknowledge a broad range of human experience and need. Freire (2000) and Fenwick (2010) have written broadly on modes of cultural reframing, which permit the burgeoning and empowerment of individuals who are most at risk within society. A post-structural analysis of the political, social and economic institutions that define social hierarchies, distribution of wealth, access to education and notions of family, actualized as the natural order of

44 (Ledux,1996).
45 (Gramsci,).
things, enables the restructuring of new and more inclusive concepts of human potential, experience and engagement within society.

Awareness of the social, economic and political imperatives that shape social structures, belief systems and human activity afford insight into the way in which social worlds are deliberately constructed, rather than naturally occurring phenomena. This insight offers opportunities to challenge dominant ideologies that establish and promote standards and behaviours specific to individuals or groups. For example, the understanding that people with Alzheimer’s are patients is a widely held and promoted belief. In fact this is not the case. Similarly, it is common, in my experience, for people to assume that people with dementia are beyond new learning. Such a belief automatically eliminates this group from social spheres, i.e., colleges and universities that provide formal and informal learning opportunities for adults. How might alternative views of people with dementia change their lived experience, inform models of caregiving and enrich education?
Chapter 3
Reframing Alzheimer’s

Time heals all wounds, people said. While time changed them something closer to grace ameliorated them, nothing healed them. Time simply made another channel for the water to course down.

(Gioia Timpanelli, Sometimes the Soul, 1998, p.28)

Many current events, popular ideas and scholarly works related to neuroscience, brain trauma and education contribute to current discourses about Alzheimer’s disease, neurodegenerative diseases and communication disorders. These point to new ways of considering quality of life and function for elderly people, in particular, and for their families who confront the formidable demands and life changes associated with dementia and other neurological disorders that impact communication. The potential of the human brain, lifelong-learning, communication, technology and ageing are among the most promising and pressing issues of our time. Through a reading of these ideas, it is not only possible to reframe our concept and understanding of people with Alzheimer’s disease and Alzheimer’s-like dementia, but imperative that we do in order to raise our collective, social consciousness and improve quality of life for all. An example of such a shift in thinking is universal design theory, which is used in the design and implementation of teaching methods and strategies for people with special needs. Universal design considers simple adaptations, such as building a wheelchair accessible access ramp into a school for example. This simple adaptation, though implemented specifically for a person with special needs, proves useful to others who do not have special needs; the ramp is used by a mother pushing a stroller, or by a teacher who is wheeling supplies or a bike for safekeeping into the building. By adapting the
world to suit those within our communities who live with disabilities, we coincidentally improve quality of life for all.

Diana Friel McGowan, a woman diagnosed with early-onset Alzheimer’s at the age of 50, fought long and hard to function at work and at home while her memory slipped away. Her adaptive spirit and quest to make sense of her experience drove her to write a memoir of her life with Alzheimer’s, create a foundation and write a curriculum for others struggling with dementia. Despite the challenges of her altered life of gradual cognitive diminishment, she fought to live a full life and bring her story to light. The reading of her courageous narrative alters fixed ideas about people with dementia as lost and without value in our society, permitting a vision of new landscapes to explore for those with neurodegenerative diseases. In his book, *Life in the Balance*, Tom Graboys, an eminent cardiologist from Boston, continues to fight the ravages of Parkinson’s disease and the accompanying Lewy body dementia, which is slowly diminishing his memory, recall and ability to communicate as he once did. Yet, still impressive, his credo is to stay “vertical” and remain as connected and active as possible with the love and support of his family. The personal memoir of Jean Tyler who cared for her husband Manly for 15 years at home after he was diagnosed with Alzheimer’s is another powerful testament to the strength and motivation that exists in one with this devastating disease.

---

46 (Friel-McGowan, 1994).
47 (Graboys, 2009).
48 As he stated in a note to me, after I interviewed him.
49 (Tyler, 1993).
Near the end of his life, Manly resided in hospital in what may be described as a twilight sleep. Whether he was comatose or vegetative, he lay unresponsive and silent for weeks. Yet, the life force was aroused within him at a point in which death seemed imminent; his wife was advised to come to the hospital immediately. Once there she spoke to Manly, quietly telling him that their daughter and son were on their way to the hospital. Their son, Steven, who lived in Panama, would come as soon as possible. To the astonishment of the family and the medical staff, Manly did not die as expected. In fact, his vital signs began to improve – heart rate and blood pressure rebounded. Near comatose, his body became restless and hot with agitation. Within two days Steven arrived. He went directly to his father’s side, held his hand and began to speak. He told Manly that he was the best father that a son could have, gently telling Manly that he loved and forgave him for all the anguish that he had caused.

Manly’s personality had changed quite dramatically in the early stages of the disease, causing him to experience rages and act out violently toward Steven. This caused a profound and painful rift between the two, ultimately causing Steven to leave home while he was still in high school. In the quiet moments afforded to Steven and Manly, they made their peace. Steven was able to forgive his father and reclaim the bond that had once existed between them. A nurse who entered the room was amazed to see tears streaming down Manly’s face as his son comforted him. The manifestation of these flowing tears, otherwise unlikely in a severely dehydrated man, signified a remarkable presence in Manly Tyler who refused to die before hearing the voice of son one last time and to receive his forgiveness. The light of consciousness had not
extinguished until the moment of death, which quickly followed after the reunion between the estranged father and son. Truly, we can only wonder about the inner life of a person with dementia. Attributing persons with Alzheimer’s disease with the qualities of whole, feeling and responsive personhood is not fool’s play. Rather, it serves to elevate the person, creating opportunities that may enhance communication, however subtle, and positive life experience.

Other writers, including Michael Ignatieff\(^{50}\) and Lisa Genova\(^{51}\) have imagined what the inner life and experience of a person with Alzheimer’s might be. In Still Alice, Genova (2009) paints a vivid image of the tragedy and far reaching consequences of early-onset Alzheimer’s. Yet the protagonist Alice retains a semblance of order within the changed landscape of her mind, reconstructing her sense of identity and the identities of those among her family. As the disease progresses, she views her husband simply as the man who lives in the house, and her daughter as the dancer. While she no longer understands the familial connection that exists between herself, husband and daughter, she understands that they are trustworthy players in her life story. This enables Alice to live a relatively joyful life, despite her gradual loss of insight, capacity and cognition. Genova’s (2009) portrayal of Alice is balanced against the perceptions of her family and their acceptance and love of Alice as her personality changes. Ignatieff (2002) also explores the complexity of family relationships altered by Alzheimer’s. These stories coupled with other accounts of true-life struggle, along with developments in the field of neuroscience spark an element of hope, not only for an eventual cure, but perhaps more

\(^{50}\) (Ignatieff, 2002).
\(^{51}\) (Genova, 2009).
importantly for the adoption of perspectives that examine neurodegenerative diseases from a position of positive and affirming actions that support self-efficacy in caregiving, and strive to bring to light the essence of the person who remains present to life.

While there is absolutely no question about the catastrophic nature of Alzheimer’s disease and its progression, questions about what occurs in the mind of a person with Alzheimer’s dementia throughout its stages persist? To what extent do awareness, insight and presence of mind continue to function in persons with Alzheimer’s? How do external perceptions, of Alzheimer’s and those with the disease, impact upon caregivers and care recipients? How does languaging influence caregiver and care-recipient behaviours and quality of life in people with dementia?

Language is powerful and evocative, as much as it is subtle and deeply embedded in notions of truth, so much so that we do not question its meaning. The word ‘patient’ is one such example that describes persons “who are under medical care or treatment”, who visit doctors and/or reside in hospitals, medical clinics and homes for the aged. Medical personnel speak about their cases and their patients who are defined by the medical community as unwell, sick or battling a disease. Indeed, there is truth to this construct. People who live with diseases may very well be unwell, critically or gravely ill. However they remain, first and foremost, persons who experience their illness on physical and emotional levels. A dictionary definition describes the patient as a person under the direct supervision or care of a physician. Yet people who visit

\(^{52}\) (Swain, 2010).
doctors are not necessarily unwell and need not, even when the person is gravely ill, be solely understood through the concept of illness. These questions reside at the heart of this research study and thesis.

Contributing to the growing popularization of neurobiological anomalies is the publication of remarkable stories in the news involving the brain. Reports of the continued recovery of congresswoman Gabrielle Giffords who survived an assassination attempt, in which a bullet passed through the left-side (the language centre) of her brain, and the no less remarkable story of Captain Trevor Green\textsuperscript{53}, assailed by an axe-wielding man during a peace-keeping mission in Afghanistan, boggle the mind. The blow to Green’s head left him with a 5cm gash to surface areas of his brain, including the motor cortex, which governs movement. He too continues to recover cognitively, psychologically and physically from this otherwise catastrophic trauma. Sheer dogged determination and resiliency must certainly have contributed to these astonishing outcomes.

When reading these stories it is hard to overlook the power of positive thinking. However, it is also important to recognize that both of these high profile individuals were – and continue to be – the benefactors of state-of-the-art medical services and the highest calibre of care and support. Indeed, these factors are crucial to wellbeing, quality of life and recovery. Without access to these resources the outcomes for Giffords and Green would most certainly have been more serious.

\textsuperscript{53} See The Toronto Star July 16, 2011.
As well, an abundance of books on neurobiology and related phenomena may be found on bookstore shelves. Once under the purview of medical professionals only, access to information about the brain and neurobiological studies is now readily available to the public. Many of these books are written in the form of personal narratives that inspire awe and wonder about the human mind and its ability to recover from trauma. Jill Bolte Taylor,\textsuperscript{54} neuroanatomist, educator and spokesperson for the Harvard Brain Tissue Resource Centre has written one such account about her survival and recovery from of a major haemorrhagic stroke at the age of 37. Once stabilized in hospital, Bolte-Taylor’s (2009) mother came to care for her. She describes in retrospect her state of mind at the time.

She looked me straight in the eye and came right to my bedside. She was gracious and calm, said her hellos to those in the room, and then lifted my sheet and proceeded to crawl into bed with me. She immediately wrapped me up in her arms and I melted into the familiarity of her snuggle. It was an amazing moment in my life. Somehow she understood that I was no longer her Harvard doctor daughter, but instead I was now her infant again. (p. 87)

After 10 years of rigorous physical and cognitive therapies, she returned to her job at the Indiana University School of Medicine and wrote her unique story in which she explores the brain’s remarkable potential to re-learn even after catastrophic injury to the left-side of her brain.

\textsuperscript{54} (Bolte-Taylor, 2009).
Crime novelist Howard Engel\textsuperscript{55} wrote his memoir entitled, *The Man Who Forgot to Read* (2008) after suffering a stroke that resulted in a condition known as *alexia sine agraphia*, which leaves him unable to read. Through dedicated and disciplined effortful work toward his recovery, he too has returned to work as a novelist, gradually increasing his capacity to function. While able to write, he remains unable to read and edit his work.

Physician and teacher Moshe Feldenkrais\textsuperscript{56}, the father of the Feldenkrais method known as Movement Through Awareness, wrote *The Case of Nora* (1977). In this account of his treatment of Nora, a woman in her 60’s, Feldenkrais reflects upon the process that restored Nora’s ability to communicate after suffering a stroke. Once again, despite serious neurological trauma, rehabilitation occurred through what is now called functional integration. This method builds awareness of body and mind through subtle techniques that attune body and mind in such a way as to engage and support the nervous system at its various levels. Using integrative body-mind methods as a path for Nora to re-learn the language that she had lost, she was able to return to life in a functional way.

Norman Doidge (2007), author of *The Brain that Changes Itself*, examines the neuroplastic capacity of the brain to create new synaptic pathways to memory, language and physical function lost to trauma. A spate of other books, written by Temple Grandin,\textsuperscript{57} Oliver Sachs,\textsuperscript{58} Joseph LeDoux\textsuperscript{59} and Daniel Levinth,\textsuperscript{60} have brought the

\textsuperscript{55} (Engel, 2008).  
\textsuperscript{56} (Feldenkrais, 1977).  
\textsuperscript{57} (Grandin, 2006).  
\textsuperscript{58} (Sacks, 2007).  
\textsuperscript{59} (LeDoux, 2007).  
\textsuperscript{60} (Levinth, 2007).
complex world of neurobiology to the fingertips and imaginations of the average person with an interest in neuroscience.

As an educator, I am alert to any writings, popular and otherwise, which may assist me in developing a well-informed understanding of students of any age. I am often astonished when comparing my younger and older students, who struggle with cognition, memory and focus in different ways. To my surprise, I find that my adult students with Alzheimer’s possess a far greater capacity to focus and maintain their presence than my teenage students. Recognizing this caused me to wonder how this could possibly be the case.

One afternoon in class, while attempting to gain the attention of a large contingent of students in a Grade 8 gifted class, I scanned the room looking carefully at the students’ facial expressions while they talked. It became clear to me that many of these young people were held captive by their minds, full of noise! It was as if I could hear the transmission of sound resulting from the busyness going on within their heads. Indeed, these youth do nothing but struggle to focus because there is so much going on internally and externally. Conversely, my elder students with Alzheimer’s have much quieter minds caused by the silencing effect of dementia. Sad as this may be, the benefit of such a quieting permits and enables an awareness that few of us know.

People with Alzheimer’s experience isolation and, because of this, they passionately long to connect with others. In addition to this motivation, they often

59 (LeDoux, 1996).
60 (Levitan, 2007).
experience a heightened response to emotions and sensory input. These attributes are a huge advantage for educators who choose to offer educational programs to people with Alzheimer’s, because they have students who are motivated and in tune with subtleties that others may not perceive. Thus we stand to learn from people with Alzheimer’s through our common language and through our shared and uncommon experience together. If we choose to attune to people with Alzheimer’s, we may come to understand more about their experience, and gain insight into their cognitive processes to improve their quality of life.

To consider a person with Alzheimer’s as a whole, interesting and adaptive person who is able to learn, despite cognitive limitations, may seem an affront to those among close family and friends who have known the afflicted person throughout their lifetime. Yet, to those outside of this intimate circle such a view of comparison does not exist. Well-informed caregivers, activation staff, teachers and healthcare practitioners who work with people with Alzheimer’s in day programs, assisted living residences and clinics acknowledge, accept and foster the personhood and efficacy of their members, residents and patients. Certainly, there are limitations to the self-efficacy that a person with Alzheimer’s may claim. However, repositioning persons with Alzheimer’s from a place of passive victimhood to one of active participation enables the possibility of new affirmative roles for the elderly and the disabled. Moreover, persons with Alzheimer’s may be afforded opportunities to participate in broader social circles and in the management of their lives. Perspectives that regard persons with developmental disabilities as valued, contributing members of society are embedded within educational
traditions and standards in Canada and other countries in the developed world. The notion of inclusion in the education of children and adults is a foundational principle of education policy. Furthermore, the theme of inclusion is championed by the United Nations Educational Scientific and Cultural Organization (UNESCO), which states that:

Inclusive education is based on the right of all learners to a quality education that meets basic learning needs and enriches lives. Focusing particularly on vulnerable and marginalized groups, it seeks to develop the full potential of every individual. The ultimate goal of inclusive quality education is to end all forms of discrimination and foster social cohesion.

UNESCO also acknowledges the vital link between lifelong learning and social wellbeing stating that, “adult education is now seen as a key in the economic, political and cultural transformation of individuals, communities and societies in the 21st century.”

The ability to adapt was observed by Charles Darwin as the central feature of survival for living species. Humans among this vast realm of life must also adapt in order to survive and experience the fullness of human potential. Learning, according to psychologist Jean Piaget, is also an adaptive process that occurs in response to environmental changes within a person’s surrounding world. People with Alzheimer’s, particularly those in the early to middle stages of the disease, are continually responding, adjusting and adapting as they work to function and survive to the best of their ability. While cognitive processes slow, these individuals strive to connect throughout all phases of the disease progression.

As stated in Global Report on Adult Learning and Education (2011) “adult education is now seen as a key in the economic, political and cultural transformation of individuals, communities and societies in the 21st century.”
For people with Alzheimer’s the ability to interpret conversation – a complex cognitive task that most of us take for granted – gradually diminishes, causing the person to process, interpret and respond to the spoken word more slowly and with greater effort. It is as if the mind becomes myopic – short sighted – unable to bring into focus the panorama of meaning created by the themes and textures embodied in language. Each word represents a whole new realm of meaning. The textural meaning of words – their depth – is gradually lost in people with Alzheimer’s. However, understanding can still be achieved by offering the person support, encouragement and an ear, while they begin to recognize, distinguish and attempt to understand the fullness of a comment, question or simple command. A person with Alzheimer’s must grasp its meaning, as if in hand, before they can respond or act in a meaningful way. Sometimes the people that I work with will ask me to repeat “the last part” of what I had said. Understanding therefore is transient and fleeting, coming and going in unpredictable rhythms. Beyond attempting to comprehend words, people with Alzheimer’s read facial expression very well, responding to open affection and welcoming tones of speech.

---

62 (Keller, 1905, p.19).
Chapter 4
Student-Teacher Dynamics: Recognizing the Self in the Other

Inter-Subjectivity

Roger’s notion of inter-subjectivity speaks to the dynamic that unfolds between a teacher and student throughout their interaction. The dialogue that manifests in this manner is fuelled by the conscious and unconscious lived experiences of each. Thus, the psychological complexity of this participatory and mutual work adds to the complicated task of teaching and learning. Without delving further into the interchangeable nature of these roles, the salient message is that teachers and learners influence one another in both subtle and overt ways throughout their work together. Each is bound by the subjectivity of their experience as self. That is, our psychological, physical and emotional identity, much of which becomes entrenched at unconscious levels informs our interactions and responses to others. In teaching, inter-subjectivity is a phenomenon of which educators become acutely aware when confronted by their students’ – and their own – responses to issues that arise within the dynamic of the classroom. Educators are reminded that their students also possess powerful and evocative constructs of identity that inform every move, conscious and unconscious. Recognizing and developing an awareness of the ways in which teachers and learners bear influence upon the other increases the potency of the learning experience. In my teaching of adults with Alzheimer’s disease, I represent myself as a collaborative partner who stands to learn as

---

63 (Rogers, 1989).
64 (Rogers, 1989).
65 (Piaget, 1972; Vygotsky, 1993).
much as my students from our work together, drawing attention to shared experience and co-creation of knowledge and expertise. While my students at the day program recognize my ability to guide them through an artistic process, they also acknowledge and take pride in their accomplishments.

Lowell is delighted today. He seems to have come back to life since I saw him last week. I’ve noticed a decline in his personality, which is usually so cheerful. He is more engaged today, finding satisfaction in the art-making process once again. At the end of the session, we looked at his work and he commented on the quality of his paintings, “This is good,” he said, while placing emphasis on the word “is.” He went on to say to me, “you should be proud of yourself.” “Why Lowell,” I asked. “Because all of this is because of you.”

I certainly do feel very proud of this work, not only because I am achieving something that is very important to me, but also because I am proud of the work that my students and I accomplish together. We experience jointly a deep sense of satisfaction and, through this, we support one another. The teaching/learning process benefits and, in fact, relies upon this kind of mutual exchange. In the absence of this mutual recognition and celebration, both teaching and learning becomes little more than a chore. In this way, teaching within a new frontier, such as I do with people who have Alzheimer’s, the possibilities for growth seem without limit. In more recent weeks, Lowell has spoken about his learning and perception of self as a person who is able to express himself through painting. As I watch and instruct him, I can see that he is
learning at procedural and cognitive levels despite his Alzheimer’s. I have witnessed this several times now.

In the early stages of the study, I showed my participants how to wet the watercolour paper that they were going to paint upon. The process involves selecting a sponge, dipping it in water, squeezing out the sponge and then applying the sponge to paper moving it from left to right, down and across the paper, and from left to right again until the paper is nicely dampened with water. At first, I demonstrated the process. After I had done this a few times I suggested that each participant attempt this independently. One by one, I circulated around the table assisting and reminding each person of the steps. In time, Lowell and the others learned how to wet the paper on their own. When I was able to address the whole group in a general way, saying, “okay, now wet your paper,” each one picked up a sponge and dipped it into the water without assistance, I knew then that they had learned this method. Each week this skill was reinforced and practiced.

_Lowell was in very good form this evening. He is delightful and keenly interested in the project and painting. He requires a fair bit of facilitation with mixing paint, although I am sure that he can take this on in time._

Lowell confidently wets his paper in preparation for painting in response to a simple, clear command. On a deeper level, I am struck by Lowell’s desire to reflect upon his work. On these occasions he will often speak about what I have taught him about use of colour and composition. Despite his progressive loss of memory, ability to
write – all of which I have witnessed over the past 10 months – he is able to discuss his work in an insightful way. I attribute much of this to the elements of our relationship that is contextual and consistent. The context is stable, familiar, friendly, safe and failure free. Furthermore, the space itself, the common room at the adult day program, is bright and cheerful. In terms of consistency, throughout the study I appeared at the centre twice weekly on regular days and at regular times. Further to the consistency of my presence, I set up the work area in a similar way each week with only minor variations. Each participant has an established place at the art table, and each place was set with familiar materials: a paint set, brushes, art board, paper and water. The stability of all of these measures serve as reassurance for any student, even experienced painters, who are likely to feel some level of anxiety prior to the beginning of class. In people with dementia, establishing consistency is vital to success all around. The reinforcement of these material routines, coupled with the emotional qualities that define the social interaction of a group such as ours, contribute to an affirmative and joyful social experience for all of the persons involved. Within this context, a person with Alzheimer’s comes to know others in profound social and emotional ways.
Figure 12. Lowell proudly shares his work with others who attend the adult day care program. (photographed by K. Downie).
To illustrate the power of embodied knowing, I return to the story of Emma and the way in which she responded to the sight of the art supplies, laid out before her, as the activationist attempted to settle Emma into the day’s program. The sight of the art supplies evoked an embodied memory, a feeling that reassured her. Emma’s sense of the painting experience was ignited once she saw all of the interesting and pleasing materials set out before her.

At other times, it was clear that Emma had many ideas in her mind, yet she could not articulate these in a way that was easily understood by others. To understand Emma, it was necessary to listen with care, ask questions for clarification and establish some physical contact, such as touching her hand. These strategies, along with eye contact and patient reassurance went a long way to piecing together the meaning behind her words. Again, gentle touch and familiar tones of voice trigger a felt response, a physical, embodied memory.

As the disease progressed, her agitation and distress also intensified. In time, her family would be asked to withdraw Emma from the program until she reached a more settled stage. While it is a difficult to ask family members to remove their loved one from a respite program, it is necessary to uphold the excellent standard of care and maintain a collegial and safe space for all.

When I heard this story I was delighted because it affirmed my belief in the purpose of the program that I had developed. It also demonstrated that the social aspect

---

66 (Kontos, 2009).
of the art program contributed to the instillation of a kind of memory, facilitated by social and emotional engagement. When Emma saw the art supplies on the table, it may well have triggered a visual memory. However, more importantly, I believe that it evoked positive associations that Emma sensed and felt in her body.

The experience of friendship, acceptance and sharing were intrinsic to the art classes. Indeed, painting within this context becomes a joyful and safe social interaction. Similarly, while Emma could not identify me by name she knew me very well on an emotional level. She associated me with a broader context imbued with the warmth of my smile, lively conversation and collaborative painting, hand-in-hand. The emotions contribute to the learning process and the acquisition of memories, affected through the release of neurotransmitters and hormones delivered throughout the brain. Neurotransmitters and hormones serve as modulators and mediators between input derived from external sensory experience and internal processes within the mind.

The amygdala is the emotional seat of the brain. In response to emotional arousal, chronic stress or fear, its response turns on “all sorts of bodily systems” which in turn either heighten memory or diminish the brain's capacity to function effectively. Emotional arousal often results in the release of the neuromodulator adrenaline, which may have a positive effect upon the creation of memories. Chronic stress on the other hand results in the release of cortisol, which curtails learning and the formation of new memories. Conversely, feel-good endorphins and the hormone oxytocin heighten

---

67 (LeDoux, 2010).
68 (LeDoux, 2010).
69 (LeDoux, 2010).
feelings of pleasure. These are released in response to creative, collaborative activities. As a painter, I have experienced first-hand the rush associated with the release of endorphins, after resolving a particularly difficult aspect of an image that I was struggling to create on a canvas. I was elated! Feelings of closeness and bonding are also facilitated through the effect of oxytocin. The bond between mother and child is triggered through this hormone. As well, people who sing together forge powerful bonds in a similar way. The act of choral singing also prompts the release of oxytocin.

Bonding, trust and feelings of pleasure therefore support communication, learning and collaboration. It stands to reason that persons with Alzheimer’s and engaged in affirmative and creative social interactions receive emotional and cognitive benefits. Learning in people with dementia begins with the building of trust and mutual respect; it is from this essential foundation that reciprocity may bourgeon.

**Mutuality**

The inter-subjective nature of human interaction can be potent and often problematic in life and at school, as the dynamic confrontations that we experience in our interactions with others may not necessarily be satisfying or mutual. Thus, it is simply understood that individuals respond to and influence one another in complex ways. In order to establish more satisfying interactions among those with whom we work and live, it is important to develop an awareness of mutual interests and goals. Attaining insight into common experience and recognition of mutual goals enables positive learning experiences, not only for the student but also for the teacher. This notion, the inter-changeable roles between teacher and learner, is central to mutuality
and the growth of reciprocity, which illuminate the experience of learning in rich and profoundly satisfying ways. To begin, mutual respect and the notion of equality must be established through a teacher’s clear statement of intention and subsequent actions.\textsuperscript{70}

Within the context of adult education, particularly adults with Alzheimer’s, I hold the deepest respect and reverence for my students. This is expressed in many ways: from being punctual on my teaching days; setting up the work space in an organized manner; warmly greeting my students by name, and so on. In terms of my instruction, I speak to each of my students individually to confer with them, establish goals and to gain a sense of their mental and emotional status at the time. I always keep in mind the dignity, proficiency and expertise of my students to acknowledge my place within our relationship as a person who stands to learn from them as well. Thus, the teaching process is invitational, consultative and respectful. To recognize the interchangeability of teacher-learner roles is to position oneself as humble and empathic. It is from this place that reciprocity in teaching and learning emerges.

\textit{Reciprocity}

It is well noted in developmental psychology that the relationship between a student and his or her teacher is informed by each person’s unique circumstances and life experience\textsuperscript{71}. The psychosocial development of a child is specific to his or her experience of the world influenced and interpreted through family relationships, culture and the environment.\textsuperscript{72} Therefore, the student/teacher relationship is viewed as dynamic

\textsuperscript{70}From a pedagogical perspective, establishing a tone of mutual respect between the self and students is always essential to the success of both the teacher and learner. However, in teaching children the complex notion of hierarchy also rears its head. This is not the case in my teaching of adults. Thus, at the moment I speak specifically to teaching my elder students with Alzheimer’s.

\textsuperscript{71}(Vygotsky, 1993).

\textsuperscript{72}(Vygotsky, 1993; Piaget, 1972; Rogers, 1989).
and potentially loaded with psychological and emotional content. As such the student and teacher co-create an inter-subjective phenomenon\textsuperscript{73}, which may produce a rewarding or disconcerting experience, mutually or otherwise. In the case of a mutually rewarding experience, the relationship may be regarded as reciprocal, bearing mutual respect and acknowledgement. Further to this phenomenon is a sharing of ideas and a joint willingness to trust the perceptions and guidance of the other. It is fair to say that while the student/teacher dynamic is always inter-subjective, it is not always reciprocal in nature. The development of reciprocity is an effortful endeavour, embarked upon through consciousness or other impetus by both the student and the teacher.

Remarkably, this consent has been exchanged and experienced in abundance throughout my work with members who attend the adult day program for persons with Alzheimer’s disease and other forms of dementia.

It is important to recognize the phenomenon of mutually shared experience, particularly within the context of learning. Reciprocity, the engagement of individuals who seek to understand one another through a shared activity, particularly in the care of elderly people with Alzheimer’s disease, offers opportunities for understanding the nature and dynamic of inter-subjectivity\textsuperscript{74} within the educational context. This is to say that the exchange of knowledge between a teacher and a learner is certainly inter-subjective and may hopefully become reciprocal.\textsuperscript{75} Bianchini identifies the actors of this inter-subjective dynamic as ego and alter ego.\textsuperscript{76} In this way, the teacher and learner

\textsuperscript{73} (Rogers 1989).
\textsuperscript{74} Rodgers, 1989; Vygotsky, 1993).
\textsuperscript{75} (Bianchini, 2011).
\textsuperscript{76} (Bianchini, 2011).
experience self as ego and the other as alter ego. Each, through the construction of awareness, learns to attune to the other and gain empathy, insight and ability to participate in a shared or bi-directional\textsuperscript{77} cognition.

While educational dynamics always bear the weight of inter-subjectivity, mutuality and reciprocity do not necessarily follow. The phenomenon of reciprocity recognizes and acknowledges both the conscious and unconscious tone of the actors. Indeed, the weight of the unconscious, that which motivates both teacher and learner within the educational context, may easily remain unrecognized. It is during times of unrest or conflict that the teacher must ask herself what appears to be at play both within and without the self. The complexity of personalities, life experience and precious little one-on-one time with students leaves many of these questions unanswered. However, within the context of education for people with Alzheimer’s dementia, inter-subjective reciprocity is well served by the possibility of focused one-to-one exchange, which in turn facilitates the bonding and learning potential.

Within a framework of mutual trust and respect, reciprocity takes hold within the individuals immersed in the process of inter-action. Mindful engagement, rooted in reciprocity, permits and facilitates a responsive dialogue between the partners who collaboratively learn from and teach the other. Thus, these roles are inter-changeable, leading each of the actors to assume the dual of roles of teacher and learner. They are equally active participants equally invested in the process of exchange. Each stands to gain from such a creative and open-ended experience. The model (see figure 10) is a

\textsuperscript{77} (Bianchini, 2011).
visual representation of the dynamic that I have described. Four circles converge around a central circle marked with an R, representing Reciprocity.

Reciprocity occurs when each participant is present to the other. This means that both are attentive, attuned and engaged with the actions and words of the other. Through engagement and response, each person interacts with the purpose of learning from the other. The two circles that are vertical to the horizontal axis of the diagram represent the inter-changeable roles of teacher-learner and learner-teacher. The triad of words external to the five circles represents the social, personal and relational domains affected through the enactment of reciprocity.

Reciprocity is carried forth, emerges or develops as we attend to the other by degrees of attunement, as we become sensitized to the other. Paying attention is essential to the development of reciprocity. While unconscious behaviours emerge without conscious effort, attaining reciprocity is effortful. It requires mindfulness, patience and the ability to be present to the moment.
Figure 13. Reciprocal Learner-Teacher Model (created by Kathleen Downie and Jennifer Polo).

In levelling the playing field, so to speak, several important things are accomplished. The prior knowledge and proficiency of the person with Alzheimer’s is recognized. This assumption implicitly alters the power structure that is otherwise assumed between a teacher and student. Secondly, the teacher is offered new opportunities to assume the position of the learner in order to learn new things and gain insight into self. Thirdly, the person with Alzheimer’s is inherently elevated in status through the language used by a teacher who assumes the primacy and potential of the learner. In other words, the person with dementia is not infantilized, diminished or otherwise treated in a way that interrupts his or her sense of agency.
The Gift of Presence: A Gateway to Reciprocity

I have often heard people say that volunteering has been as fulfilling for them, if not more so, as for those that they help. Hearing sentiments like these have aroused scepticism in me, but having now experienced this for myself, I understand what this means. Working with people with Alzheimer’s has proven to be a very fulfilling endeavour for me on many levels. After my first day at the adult day program, I felt elated, happy and relaxed. I accepted this as beginner’s luck and didn’t give it much more thought until the experience repeated itself the following session. After my second week of volunteering I decided to mention this reaction to my preceptor, hoping for some insight. She looked at me thoughtfully and, before she could speak, I offered a thought. It suddenly occurred to me that I was feeling so relaxed and happy because I wasn’t thinking about other pressing life issues that I might otherwise worry about while I was at the day program. I felt strongly that each person that I had spent time with demanded my undivided attention and presence. As I thought more about these encounters, I realized that a tangible feeling of attunement had developed between me and the other person with whom I was engaged. Whether we were painting, walking or chatting, a sense of presence held us together in the moment. Each of the individuals with whom I worked taught me the gift of presence and, in time, I learned how to reciprocate.

This phenomenon underlies the essence of the Reciprocal Teacher-Learner Model. It is through the practice of engagement and response that a sense of mutual purpose arises and facilitates attunement, empathy and reciprocity. I would say that achieving reciprocity in learning is foundational to a form of learning, which is
transformational in nature and deeply fulfilling for those who participate in its construction, as well as for those who are witness to its manifestation. Once again, Van Manen’s (2005) commitment to attunement and empathy help us to recognize ourselves in others. It is through this sense of recognition that we share the moment and move towards the development of insight.
Chapter 5
Moving Toward the Moment

Only the garden was always marvelous. No one had cared for it for a very long time, and it had gone back to seed and wildflowers. Its beauty was in a subtlety only careful watching could perceive.

(Gioia Timpanelli, Sometimes the Soul, 1998)

Attuning

Attentive watching and listening may give rise to a quieting within, causing the flurry of the inner voice to become still. In so doing, we can effectively attune to the needs of others who strive to communicate their needs in effortful ways. The cries of a newborn baby, the emotions of a teenager who cannot give words to their feelings, or a person with dementia all share a common experience; each lacks the ability to formulate and express their concerns in ways that are rational and easily understood. Therefore, those in the presence of such a person are called to witness, receive and respond through empathy and understanding. Yet, we are far more likely to assert our assumptions about the truth that we perceive. Silencing our own familiar sense of expertise along with the urge to problem-solve may be the biggest challenge that we must confront in response to a person who is unable to readily express their needs. Attuning is learned through practice if not conditioning.

As a child, I was trained to attune to the needs of my father who suffered jolts of tremendous pain in his spine, triggered by strong vibrations. His response to loud sounds was attributed to deafness resulting from encephalitis, a complication of mumps. I learned very early on in life that thumping on the stairs or racing around noisily on the floor above my parents’ room would prompt anguished cries from my father. Before
long, and with a great sense of pride, I learned to play, and run and climb in silence within the walls of our home. This, I did to assuage my father, to mitigate the potential of any future pain that I might cause. More recently, I recognize this early childhood training as a valuable gift that has enabled me to attune to others.

Indeed, the ability to attune to people with Alzheimer’s is extremely helpful and of mutual benefit. During moment of intense listening, time falls away revealing the quiet pulse of time in motion. Locked in a gaze, we jointly focus as we try to make meaning. Listening to words, their emotional quality, and responding to subtle movements – a squeeze of the hand, a gentle pull, a sense of tension or a smile – all contribute to a conversation like no other.

Attaining mindfulness requires us to begin anew and forget all that we hold as knowledge. Jon Kabat-Zinn\textsuperscript{78} states that we see what “we believe is in front of us.” This is to say that our perceptions, filtered through our conscious and unconscious experiences of the world, are shaped by our beliefs and assumptions.\textsuperscript{79} In the same way Gioia Timpanelli’s (1998) vision of the garden and its beauty amidst its unkempt wildness, speaks to that which is neglected, no longer viewed as valuable or precious. To the careful observer the beauty of the garden is resplendent. Kabat-Zinn’s (2005) notion rings true for me, as I often say to my young students, “draw what you see, not what you think you see.” School children often draw almond-shaped eyes while creating self-portraits or drawings of their friends. While this seems natural, and close

\textsuperscript{78} (Kabat-Zinn, 2005).
\textsuperscript{79} (Kabat-Zinn, 2005).
enough to reality, careful observation of the human eye reveals bends, lines and folds that belie the smooth curved shape that is often assumed. Portraitists are trained to observe unique subtleties embodied within their subjects, and to respond to these qualities that differentiate them from others. From the fine-lined bends and folds that surround the human eye to fleeting gestures that sweep across the face, the mindful observer is able to discern the character and emotional nature of the person within their gaze. Kabat-Zinn (2005) reminds us that our pre-conceptions, buried deep within the unconscious mind, shape our view of the world.

Similarly, assumptions are held about Alzheimer’s and its impact upon the cognitive function of those with the disease. Confronting these beliefs is challenging while many individuals with the disease become isolated, either out of their own fear or in response to the expectations and demands imposed by society. While some people with dementia are able to remain within the familiar and safe boundaries of their own homes, the demands of round-the-clock care provided by family members or personal care workers, is exhausting and expensive. For this reason, family members must often resort to the services provided by residential homes for the aged. While institutional care offers many benefits for both those with dementia and their family members, the thorny issue of deeply engrained ideas associated with ageing and illness persist. This is further compounded by the loss of inter-generational family-life, stemming from industrialization and the modernist impulse\(^8^0\) contribute to what seems to be a natural breech between the young and the old. Even the seemingly ubiquitous word *Alzheimer’s*  

\(^{80}\) (Kearns, 1987).
conjures fearful thoughts of contagious disease or certain diminishment of mind associated with ageing. These ideas considered it is not surprising that those with dementia are made invisible.

My own experience with people who have Alzheimer’s disease has brought my fears surrounding dementia to their feet, as well as the penetrating image of lost and absent souls. The reality of Alzheimer’s, as I have seen it, could not be further from the truth. As an outsider, not the daughter, niece or friend of an elder person with Alzheimer’s, I am spared the haunting loss that can be experienced by a family member of a person with dementia. I am permitted the privilege of accepting and enjoying the person that I have come to know as a person with Alzheimer’s, spared the personal memories of who the person was in prior years.

Kitwood’s perspective of persons living with Alzheimer’s dementia reminds readers that existence in the presence of Alzheimer’s continues in many ways which reflect whole, valued and valuable individuals who benefit from, and contribute to diverse social engagement. Indeed, Kitwood’s (1997) contribution to the care of people with Alzheimer’s, within nursing homes and residential care facilities, has been influential, emphasizing the importance of person-centred care. Furthermore, in placing the person first our attention is drawn away from the concept of the patient who embodies illness. Rather, the person viewed as a whole individual is the embodiment of many attributes of which illness is one aspect. Positioning those with Alzheimer’s as

81 (Kitwood, 1997).
82 (Kitwood, 1997).
adaptive learners, capable of participating in and benefiting from educational programs, extends from Kitwood’s (1997) commitment to the support of personhood and identity in people with dementia, despite their gradual and progressive loss of memory, language and function. To accomplish this paradigm shift it is important to examine collective assumptions about ageing and dementia and to consider the social and economic function of languages and stereotypes that have served to make invisible diseases that affect the elderly. By questioning and reconsidering social and economic imperatives that drive policy, the funding of social programs and social health systems, we call attention to the role and place of the elderly within families and communities at large.

In attempting to become more mindful of the experience of elderly people in a variety of social settings, particularly people with dementia, it is possible to borrow from the perspectives of Jon Kabat-Zinn (2005), Judith Kestenberg (1967) and Moshe Feldenkrais (1977) all of whose work bears some similarity in its shared concern for developing awareness of sensory experience outside of the self. As we cannot truly know about the experience of others who have Alzheimer’s, it is essential to become more familiar through careful observation and attuning. The works of physicians Judith Kestenberg (1967) and Moshe Feldenkrais (1977) inform the process of sensitizing the self to others through mindful observation and practice. The research of Kestenberg (1967) and Feldenkrais (1977) has contributed to significant developments in educational theory in interesting and unusual ways, through methods derived from careful observation of the body in action. For example, Kestenberg (1967) trained pregnant women to observe and note the subtle movements of their babies in utero.
These disciplined observations attuned participating mothers to their unborn children, and helped Kestenberg (1967) to characterize movement patterns\textsuperscript{83} to which she would later attribute qualities of “tension” and “flow.” The movement patterns that she identified in this way contributed to a method of communication that could be used to enhance the relationship between mother and child after birth. For example, a mother recognizing the sucking rhythm of the infant at the breast could replicate this pattern by gently squeezing the child’s arm. In times of distress, this rhythm could be used to calm the child who embodies this rhythm naturally.

In working with and teaching people with Alzheimer’s, we can learn from Kestenberg’s (1997) model of observation, which looks to the subtle embodied qualities and nuances of individuals as an entry into communication, bonding and developing trusting and profound relationships. Trust is perhaps the most important aspect of shared learning experiences. Without it, the learner is never free to truly express deeply held views and beliefs.

\textsuperscript{83} (Kestenberg, 1977)
Chapter 6
Learning Theory

There are many kinds and ways of learning. Some illiterate men have learned more and better than you and I. There is learning of a skill; there is the kind of learning in which we enlarge our knowledge or understanding of what we already know. And there is the most important kind of learning which goes with physical growth. By this last I mean learning in which quantity grows and changes to a new quality.

(Feldenkrais, 1977, xiii)

Supporting Identity and Personhood through Learning

Feldenkrais’ (1977) thoughts about learning are reflective of his profession as a medical practitioner who acknowledged the body as an instrument of learning. His statement about the embodiment of learning, as that which grows with the body in quantity and quality, certainly prompts reflection. His words, carefully chosen no doubt, speak to the integration of the mind and body as unified, integral collaborators in the learning process. Yet so often learning is assumed to be chiefly an act of the mind, the sole proprietor of cognition. Indeed, body and mind are unified extensions of one another and each plays a crucial role in learning.

The impact of loss of cognition caused by neurodegenerative disease and other forms of trauma, compel us to reconsider the importance of the body viewed as an extension of the thinking, feeling and responsive mind. In this way, Alzheimer’s has offered a tremendous opportunity. Children in the early stages of their psychological development remain integral, whole body-mind beings. It seems that this state of being is trained out of us in favour of seemingly more refined, defined and organized patterns of brain-centred thinking.
**Montessori**

Research psychologist Cameron Camp\(^84\) has proven that people with dementia may re-instate their procedural capacity by practicing skills-based activities rooted in the methods developed by Maria Montessori. The social-sensory inclination of Montessori, referenced by Camp, draws upon the child’s perspective to inform educational methods for his adult learners with dementia. The use of brightly coloured, tactile and pleasing objects and materials engage the sensory experience of the mind-body. This approach is so successful with people with dementia because sensory experience remains intact, if not heightened, in people with Alzheimer’s. The experience of touching, organizing or creating simple and attractive objects with a person with dementia can be fulfilling and purposeful as it activates embodied experience and knowledge.

At Baycrest Hospital in Toronto, family caregivers of individuals with dementia are encouraged to draw upon the visual arts to enhance communication and improve their interaction.\(^85\) Indeed, creating art and viewing art imagery as a focus of interaction with people with dementia supports new learning. This is achieved through integrating sensory and social experiences, which become embodied and tied to the feeling of pleasant interactions. While specific details may be lost in memory, it is possible to evoke a sense of place and belonging in people with dementia\(^86\) through sensory experience.

**Learning Realms**

In many ways concepts of identity are rooted in the beliefs that we hold of

---

\(^{84}\) (Camp, 1997).
\(^{85}\) (Baycrest, Visiting with Elders: Strategies to help you have a meaningful and rich visit with an elderly loved one, 2006).
\(^{86}\) (Zeisel, 2009).
ourselves as learners. Too often intelligence is tied to notions of speed and accuracy. When these skills are lacking, particularly in young children, the child’s identity as a successful learner suffers. Bloom’s Taxonomy draws attention to, and addresses to some extent, the broad capacities of the brain. His identification of the learning domains that govern procedural, cognitive and affective learning, begin to broaden the horizon of learning. While his model represents these domains as separate spheres of knowing, they are all inter-connected and relevant to holistic learning. Indeed, learning and memory are tied to the affective realm of the emotions, which trigger events in the brain that either aid or hinder the mind’s capacity to function well. Awareness of the procedural, affective and cognitive domains of learning, as defined by Bloom, permits insight into ways in which people with dementia may continue to learn. Furthermore it offers educators insight into ways in which these domains may be utilized to promote learning in people with dementia. Continued learning for people with Alzheimer’s fosters a sense of well-being and likely also contributes to improved mental status and the development of plateaus in people with the disease. Scientific studies have demonstrated that physical and mental activity can slow the progression of symptoms in Alzheimer’s and Parkinson’s disease. In the case of Alzheimer’s, plateaus – or prolonged periods of mental stasis – have been observed in people who remain both

---


physically and mentally active, as mediated through social connection and interaction.\textsuperscript{89} Maintaining active and socially engaged activity contributes to sense of well-being and opportunities for growth in those with dementia.\textsuperscript{90}

\textit{Embodied Knowing}

Embodied knowledge is also tied to the emotions, which influence various aspects of memory. Implicit, procedural memory is built in tandem with conscious effort and action. For example, learning to drive a car with a standard transmission requires effortful practice and attention to the procedures of engaging the clutch, shifting gears and accelerating and braking. In time the driver who has gained experience uses less conscious effort to operate the car, eventually relying upon intuitive and tacit knowledge. To experience this is to understand the embodiment of knowledge. Add to this mix a person’s associations with driving. These are likely full of emotion, perhaps evocative of pleasure or angst. The emotional content of the learned experience, layered with cognitive and procedural processes, informs effective modes of learning – the irrevocable and emotional sense of things, people and places that is often difficult to describe.

I witness this profound level of knowing when I greet the people that I work at the Alzheimer’s adult day care program once a week. While, these people do not know my name or remember the last time we met, they have an abiding sense of who I am, because they have learned to associate me with kindness, affection and the joyful

\textsuperscript{90} (Friel McGowan, 1994).
process of painting. This knowing is embodied and realized through the emotions, which facilitate feelings of closeness, bonding and the formation of friendships. This typifies the meaning of the affective realm of learning.

Procedural learning has an important place within educational programs for people with Alzheimer’s. Re-learning life-skills, such as setting a table, or preparing a simple meal, support social interaction, which in turn may ameliorate feelings of isolation in people with dementia. As well, procedural training has been used to help people with dementia way-find within familiar spaces, such as a residential care facility. This bolsters self-efficacy and also lightens work load for caregivers.

Learning is fundamental to human existence and survival and occurs on many levels of human experience, through various states of mind at preconscious and conscious levels of being in response to the learner’s environment. Perceived through the nervous system, emotions, intuitions and thoughts are interpreted, communicated and processed by the brain. Throughout life, from infancy humans interpret their experiences, formulate schematic constructs and communicate in response to external and internal stimuli in multiple ways. Knowledge is articulated through the spoken word and written languages, and through the intentionality of the body, which may

---

91 The release of the neurotransmitter oxytocin facilitates feelings of nurture and bonding in response to gentle touch, music and singing.
94 (Luppi, 2009)
95 (Dunagan, 2005; Kolb 2009; Freud, 1965).
96 See Piaget’s developmental theory; and Kestenberg who state that communication begins in utero.
97 (Piaget, 1977).
express conscious ideas through gestures imbued with emotion or, conversely, manifest unconscious themes in both obvious and subtle ways. The observer in these cases, particularly in the latter case, must attune to the unique quality of these expressions. Where language and speech fail, communication, intentional or not, is articulated through the corporeal, emotional being.

While embodied knowledge is a new frontier for educators and scientists, it is familiar to those within the worlds of performance and dance. These artists habitually reference the instrument of the body as an agent of communication. The body is the locus of artistic expression and the source of formal aesthetic analysis in the study of movement and awareness. Pia Kontos (2009), a research scientist at Toronto Rehab, is currently researching tacit communication and the articulation of embodied knowledge in people with Alzheimer’s. In considering the potential of learning within an embodied and experiential framework, it is possible to identify ways in which the existence of learning potential in people with Alzheimer’s may be considered, despite loss of cognitive function and in some cases the ability to communicate.

**Developmental Learning Theory: Piaget, Vygotsky and Rogers**

Piaget’s (1972) familiar classification of the stages of development: sensorimotor, pre-operational, concrete-operational and formal-operational identify distinct stages in the development of human learning from birth. These stages are essential to the construction of subjective and objective concepts achieved through the

---

98 (Kestenberg; 1967).

99 The work of Kestenberg and Feldenkrais explore methods of attuning through detailed analysis of the body.
learner’s direct experience of world. Both Piaget (1972) and his contemporary Vygotsky (1993) recognized the importance of social and cultural activity as key to the evolution of the person. From a Vygotskian perspective, the external world embodies the cultural and historical context particular to the learner, which profoundly influences and shapes perceptions and the development of self. Thus, the internal realm of the self becomes engaged with external phenomena found through the individual’s experience of the world. The learner is both influenced and influential within this dialogic relationship. Decades later Carl Rogers (1989) identified the inter-subjective nature of learning, which stems from interpersonal exchange, informed by the convergence and intersection of diverse perspectives embodied within the actors. Within the educational contexts, a teacher, mentor or facilitator is aware of Vygotsky’s (1993) principle of the zone of proximal development (ZPD), as he or she recognizes the differential between that which the student achieves with assistance and that which is accomplished independently. As we learn throughout life, the cycle of the ZPD repeats itself and becomes recognizable as individuals seek out challenges, develop new skills and attain knowledge, initially with assistance and later independently. The ZPD is crucial to this study, as manifested in the painting classes that I teach to adult students with Alzheimer’s. Similarly, Rogers’ (1989) theories reflect the inter-subjective nature of the learning phenomenon as a fluid, ever-changing interaction between the self and others. Persons with Alzheimer’s may be perceived, and, may perceive him or herself within this continuum of experience, and therefore find validation and opportunities for growth within learning opportunities.
Adult Learning Theory

Developmental learning theory bears relevance to adult learning theory, as each is process-oriented and experiential in nature. Motivation and the accumulation of proficiencies, which emanate from and inform concepts of identity, differentiate the adult learner from the child. Kolb’s (2009) learning spiral draws upon metacognition, an awareness of the self as a learner. This awareness informs methods and approaches to learning, and enables the identification of the self as a learner. The individual with a learning self-identity\(^{100}\) is empowered by the knowledge that, “I can learn.” In contrast, persons with a fixed-identity\(^{101}\) view themselves outside of the learning continuum. Kolb’s (2009) experiential learning model relies upon self-reflection and the development of metacognitive concepts of the learner-self. These perceptions are akin to epistemological beliefs,\(^{102}\) which inform the learner’s self-identity as proprietor of knowledge and beliefs about learning. In teaching people with Alzheimer’s disease, it is important to instil this notion, affirming the capacities of the learner at all times. In so doing, the individual may adopt and integrate a learning self-identity.

Intersections

Intersecting with issues related to long-term care (most frequently provided by family members and, latterly, personal support workers and homes for the aged) are the overarching beliefs and perceptions about dementia which impact directly upon the lives of people with Alzheimer’s. These beliefs often assume that persons with Alzheimer’s are without hope and incapable of functioning in meaningful ways. This deleterious

\(^{100}\) (Kolb, 2009).
\(^{101}\) (Kolb, 2009).
\(^{102}\) (Bromme, 2010).
view of the person stricken with dementia is shifting in response to a broadening social awareness of diseases that cause dementia, particularly those affecting the elderly. This awareness is in part attributed to innovative programs delivered through services for the elderly (adult day programs and residential homes for the aged) and hospitals. Among these are the Waterford Healing Arts Trust and the Third Age Foundation in Ireland, which engage in collaborations with the community at large, through inter-generational programs and collaborations with artists who work in situ through artist-in-residence programs to develop bodies of work informed by the institutional space and its purpose. Projects such as these promote the exchange of knowledge between researchers, artist-facilitators and the clientele of hospitals and other health care facilities, the intended beneficiaries of these creative collaborations. However, it is important to note that artist-researchers seek out these opportunities to inform their concerns and fuel the investigation and expression of their creative work, which is in turn mobilized publically through exhibitions.

Arts-informed research works in a similar way, as a process of investigation that uses the language of artistic expression as a means of interpreting and representing data intended for the dynamic forum of the public sphere. Engaging with broad audiences in this way promotes a reflexive discourse in response to the data-bearing artworks, facilitating a cycle of creative and transformative iterations.
The publication of personal narratives about living with dementia written by Diana Friel-McGowan\textsuperscript{103} and Tom Graboys,\textsuperscript{104} and popular fiction that conceive of what it might be like to have dementia\textsuperscript{105} have also contributed to an expanded social awareness of diseases that cause dementia. Thus, perceptions and attitudes are changing.

\textit{Teaching People with Alzheimer’s Disease: Therapeutic Education}

Controversy surrounds the notion of therapeutic education and the therapeutic “turn”\textsuperscript{106} in the education of children, adults and elders of the Third Age. Therapeutic education is perceived as a less rigorous mode of learning because its draws upon the feeling and emotional qualities of the learner.

The controversy lies in the potential marginalization of the traditional core values\textsuperscript{107} of education that aim to produce critical minded, active citizens of the future. Ecclestone and Hayes define therapeutic education as any activity that focuses on perceived emotional problems and which aims to make educational content and learning processes more emotionally engaging as therapeutic education.\textsuperscript{108} Hyland draws attention to the inherent connection between the affective and cognitive domains of learning, and LeDoux\textsuperscript{109} observes the neurobiological significance of the emotions upon learning.

\textsuperscript{103} (Friel-McGowan, 1994).
\textsuperscript{104} (Graboys, 2009).
\textsuperscript{105} (Michael Ignatieff, 2000).
\textsuperscript{106} (Hyland, 2010).
\textsuperscript{107} (Thompson cited in Hyland, 2007).
\textsuperscript{108} (Hyland, 2010).
\textsuperscript{109} (LeDoux, 2009).
Therapeutic modes of education as defined are fitting and full of purpose within the learning contexts for people with Alzheimer’s because the emotional life in people with forms of dementia is viable and even heightened. Thus, engaging in discussions and activities that draw upon emotional content may be very productive and fulfilling.

Vygotsky (1993) recognized the connection between interpersonal and affective factors, which together impact upon the cognitive development of the learner. Indeed, these interactions also influence the development of the teacher, as well as others within the learning context, in important ways. Witnessing the emergence of reciprocity within learning circles is transformational.\textsuperscript{110} Such an enactment, borne out of gentle consideration, concretely demonstrates alternative responses to situations that may well be frustrating. Teachers experience this in the classroom and caregivers experience this as well. It is easy to express anger and frustration, yet with practice, the calm associated with an empathic and compassionate view may also come easily.

Activities that draw upon and exploit emotional content are not always fulfilling. In fact creative work in particular may arouse fear and anger in a person. This is one of the reasons that I am quick to declare that I am not an art therapist, rather an educator-artist who acknowledges the therapeutic undercurrent present in the creative process.

Art therapists are highly trained professionals, well versed in psychology and the nature of creative work. They are also fully aware of the potential for volatile responses to certain processes. This is why it is essential for educators using the arts to be aware of some of the basic principles of the arts therapy, and sensitized to the learner.

\textsuperscript{110} (Mezirow, 2000).
The Third-Age

Drawing upon the presence of the Third-Age – a growing social movement that stems from the generation of baby-boomers now in the latter third of their lives – the development of educational programs for people with Alzheimer’s may parallel those opportunities that third-agers generally seek out to sustain vitality and engagement with their social worlds. Gaining access to formal and informal educational opportunities has emerged as one of several key themes for third-agers. This impetus has contributed to the establishment and proliferation of U3As – Universities of the Third-Age – in Australia, New Zealand, Great Britain and North America\(^\text{111}\) This movement speaks to a growing awareness of the social benefits of life-long learning, and its broad contribution to society, while bolstering physical, mental and emotional wellbeing.\(^\text{112}\) In addition to the satisfaction of learning is the prospect of developing new relationships and social networks.\(^\text{113}\) Therefore, life-long learning is viewed as “intrinsically valuable to human existence and quality of life.\(^\text{114}\)” Moreover, humans are predisposed to learning – throughout the life-course – as a means of survival and dynamic transformation.\(^\text{115}\) Similarly, individuals with dementia retain an instinct for survival and a desire to interpret their world.

\(^{114}\) (Butler, 1989 as cited in Williamson, 1997).
\(^{115}\) (Luppi, 2009)
Chapter 7
Teacher as Caregiver

Reconceiving the Patient as a Person

The power of language rests in its ability to assign meaning and give shape to notions of truth that are collectively accepted and understood. Words are evocative symbolic things, and problematic too, because the spoken word is shaped by its contextual use, the tone, manner and gesture through which it is delivered. Words may become self-fulfilling, as they become entrenched within their social context – whether domestic, professional, political or cultural – left unquestioned and undisturbed. Words may affirm the soul or just as easily harm as these utterances, which encapsulate ideas imbued with many biases, fall upon the ears of those who hear and become shaped by their meaning. People are thus defined by the words that describe them, sometimes so subtly so that they themselves remain oblivious to the power of the attribution.

Within healthcare, the use of the word *patient* describes a person associated with a disease, illness or condition. A person who is under the direct care of a doctor or other medical practitioner within a clinical space is a patient, rightly differentiated from others, as one who will be seen and treated by a doctor, nurse or therapist. Within this space, personhood is temporarily obscured and suspended, as the patient receives the care of the medical practitioner. Yet outside of the medical realm, persons returning to their world often remain patients. They are identified as *patients with Alzheimer’s*, *patients with Parkinson’s* or *patients with amyotrophic lateral sclerosis* (ALS), and are typically perceived and defined as sick or unwell. In fact, individuals with these neurodegenerative diseases typically continue to function, often quite effectively, at
home (the locus of the majority of their care), at work\textsuperscript{116} and within other social settings for extended periods of time, despite their prognosis and need for supportive and ongoing care. Questioning, reconsidering and substituting the use of the word patient in favour of the word person, enables a whole and more connected view of persons with disease to operate with agency within their social world. This subtle change of language influences the person’s view of self and the perceptions of others who might otherwise infantilize\textsuperscript{117} or diminish individuals with Alzheimer’s.

\textit{Person-Centred Care}

Attending to the care of persons with dementia in response to immediate and long-range needs demonstrates a leap forward in models of caregiving that have emerged over the past decade or so. The work of Tom Kitwood (1997) and John Zeisel (2009), whose theories have gained prominence in Alzheimer’s care circles, in Britain and America respectively, are contributing to the development of new ideas, models of care and understanding of people with Alzheimer’s disease. In drawing attention to the person in Alzheimer’s, and the importance of sustaining healthy identity concepts in people with dementia, both have contributed to a growing awareness of person-centred care and mature care theory. In placing the person first,\textsuperscript{118} a care recipient’s sense of agency, along with that of caring family members, becomes bolstered, validated and engaged throughout the unfolding process of care. Indeed, in many ways person-centred care becomes family-centred care in its encompassing view of the person as part of a broad social context. Not only does person-centred care ask what is best for the

\textsuperscript{116} (Friel-McGowan, 1994).
\textsuperscript{117} (Swain, 2009).
\textsuperscript{118} (Kitwood, 1997).
individual with dementia, it considers the history, nature and capacity of the person who is part of a family or other social context. In his book Dementia Reconsidered, Kitwood (1997) identifies the inadequacies of care for people with Alzheimer’s as rooted in narrow and limited social perspectives. Dementia is not only a failure of the healthy function of neurons, it is also shaped and determined by the society at large.

In very many cases, we find that the process of dementia is also the story of the tragic inadequacy in our culture, our economy, our traditional views about gender, our medical system and our general way of life.119

By enabling and listening to the voice of the individual with dementia, a whole new dimension of experience is lived, not only by the person with Alzheimer’s but by others within their circle – family, personal support workers and clinicians.

Institutional change is more likely to occur when it stops to listen to and observe the quality of life of those with Alzheimer’s who are engaged and active within their social world. Kitwood (1997) and Zeisel (2009) have actualized such a vision through their influence at academic and institutional levels.

Contact with dementia or other forms of severe cognitive disability can – and indeed should – take us out of our customary patterns of over-busyness, hypercognitivism and extreme talkativity, into a way of being in which emotions and feeling are given a much larger place.120

Hearthstone,121 a family of Alzheimer’s care homes in the United States, evokes a sense of home, signified by the hearth, through the creation of a warm and engaging environment. Zeisel (2009), a musician and physician, not only infuses programming at Hearthstone with the arts, he has also founded an organization called Artists for

119 (Kitwood, 1997, p.41).
120 (Kitwood, 1997).
121 (Kitwood, 1997).
Alzheimer’s (ARTZ) which promotes broad community access to the arts for people with Alzheimer’s disease. These programs, which take place at galleries as large as the MOMA are not only engaging, they re-claim cultural spaces for those who may otherwise be isolated. In response, public, cultural spaces also become transformed through their access to and interaction with people with dementia. This tone of mutual exchange illustrates the foundation of mature care, which is based upon cultivating reciprocity.

**Mature Care**

Reciprocal interaction between individuals in both private and public spheres stimulates a bi-directional exchange that relies upon the notion that expertise is mutually shared, permitting a sense of equality. This contributes to feelings of closeness and enables the transfer of valuable knowledge. Mature care is distinguished from both altruistic care and Egoistic care. These polarized perspectives speak to knowledge of care, as embodied either by the care recipient (altruistic care) or the caregiver (Egoistic). Altruistic care is selfless, defined by Pettersen (2011) as the Good Samaritan type of care. Such an individual looks to the care recipient for direction. In this way, the care recipient is the sole proprietor of knowledge concerning what is best. Conversely, the Egoistic caregiver is the sole proprietor of knowing and

---

122 (Zeisal, 2009).
123 The transfer or mobilization of knowledge is facilitated by viewing and articulating knowledge in new ways so as to be accessible to a broader audience. Through mutual interaction persons with dementia may learn about art seen at a gallery, and gallery interpreters may learn about people with Alzheimer’s.
124 (Tove Pettersen, 2011).
125 (Pettersen, 2011). Solatrisim is a position where one holds ‘that the other, rather than the self, is the sole existent and source of knowledge and moral worth.
126 (Pettersen, 2011). Solipsism describes the converse relationship, where the self, or the ego is the sole proprietor of knowledge and knowing.
determines without consultation what is best for the person in care. Both of these positions are clearly problematic. Mature care transcends both of these models, opting for shared consultation and problem solving where and when possible. In this way, mutual trust and the emergence of reciprocity become possible. Reciprocity is a valuable aspect of learning processes that validate personhood, nurture concepts of identity and build trust.

While it may seem that conducting a conversation with a person with Alzheimer’s, particularly one who is in the later stages of the disease, may be counterintuitive, this could not be farther from the truth. Engaging in conversation with someone who struggles to communicate verbally is not only possible, it is richly satisfying and rewarding. Having said this, it is essential to develop and build trust with the person while demonstrating warmth, acceptance and patience.

A Case for Education

Individuals diagnosed with Alzheimer’s disease come from diverse ethnic, social and professional backgrounds. Combined, these individuals and their life stories embody a vast wealth of personal experience, professional knowledge and expertise, and wisdom. The promise of progressive, cognitive decline associated with Alzheimer’s frequently results in a gradual loss of connection with social groups and increased isolation. Not only is this the case for the person with the disease, his or her family caregivers may also experience similar losses among their social group.128 This, coupled with entrenched cultural beliefs about dementia, instils feelings of fear in those with

---

128 (Pettersen, 2011).
Alzheimer’s and others who witness its toll. Yet people with Alzheimer’s may live well in excess of 10 years after their initial diagnosis and, despite the progression of their disease may remain determined to function as efficaciously and for as long as possible.

Social advocacy provided through inter-professional and person-centred care models, along with continued social engagement and participation in the activities of daily life persons with dementia experience improved quality of life and sense of wellbeing. Certainly access to diverse and inclusive educational programs for people with Alzheimer’s will also help to ameliorate the many negative impacts of the disease.

\[129\] (Zeisel, 2009).
Chapter 8
A Table for Four

Having created, developed and implemented arts-in-health programs at the Hospital for Sick Children in Toronto for many years, I had both the confidence and a strong vision of the sort of program that I could create within an adult day care setting. Starting with the Alzheimer’s Association of Ontario, I began to network and establish a list of agencies that I could contact. The Director of Education at the Alzheimer’s Society suggested that I contact Anne Powell a program director at SPRINT. We connected with one another quickly and formulated plans to meet at the Anne Johnson Health Station in North Toronto.

Establishing the Research Locus

After our first meeting, I knew that I had found the locus of my future work as a researcher and volunteer. This placement would facilitate my initiation into the world of Alzheimer’s disease in a very practical sense, as my prior knowledge of neurodegenerative disease and people with Alzheimer’s had been strictly theoretical. While well informed about Alzheimer’s disease, I knew nothing of the moment-by-moment existence of people with Alzheimer’s and their supportive caregivers, as well as others within their circle of care. Anticipating the eventual planning and implementation of a formal research study, I began a six-month apprenticeship of sorts to ‘test the waters,’ of my commitment to the research topic, gain hands-on experience of people with Alzheimer’s and learn about how my function as an educator-artist-researcher might facilitate the development of relevant programs for people with Alzheimer’s and improve their quality of life.
The Program

The initial aim of this research was to examine ways in which people with Alzheimer’s disease might continue to learn at procedural, cognitive and affective levels of experience. As the work evolved however, the dynamic relationship between the teacher and learner became progressively more interesting as a focus of the study. What did not change was the underlying purpose of the work, to improve quality of life and the care of people with Alzheimer's through the development and implementation of high quality, arts-based educational programs.

Through the offering of weekly painting lessons for small groups of individuals with Alzheimer's, all of whom attend the SPRINT adult day care program, participants gathered to take part in a series of watercolour painting lessons. A total of 10 participants provided their consent, either directly or through a family member to participate in the 12-week study. Consent was revisited prior to each session through an open invitation to “come and paint with the group.” At this time, participants would accept or decline. They were reminded that the invitation was always open and that they should enjoy any activity of their choosing. This open-invitation was very successful, as most of the participants returned to the group after taking a break. Such an open-ended approach is central to an arts-informed methodology because creative work, whether in an art studio or scientific lab, is inherently unpredictable. In the case of this particular study, the artistic process and the research are mutually informative. They coincide beautifully as inductive, discovery-based processes guided by the action and response of the researcher and participants as they communicate and respond to one another.
The Process

Prior to the beginning of each hour-long session, I converted the space allocated for my program in the common room of the centre. At a large square table, created by joining two rectangular tables, I placed five chairs (one for each participant and myself) and settings for each participant. The settings were carefully organized as microspheres for each person in the group. At this setting, I placed a painting board, roughly the size of large placemat, a set of paints, water, a selection of 2 or 3 brushes and a soft, clean sponge. Such an organized place setting accomplishes several goals. First, it is inviting for participants to see an organized, interesting space prepared just for them. The sight of the materials, which are always of good quality, clean and visually appealing set the tone for a positive experience. Second, the settings are a visual representation of a special, defined place for each participant, which may allay any anxiety that the person may have about being welcome and/or included. Finally, an organized and uncluttered space makes it easy for the participants to identify the activity and their place.
Before introducing any new ideas or changes to the existing program, I observed the interaction between staff and participants of the painting group for several sessions first. I was impressed by the gentle and affectionate relationships that existed between the participants and Carol, one of the lead activation staff, who is a talented artist. Her reverence and respect for each person in the group was made evident by her open, sensitive and congenial manner. Rather than require the group members to paint in response to a common image or theme, she started help each person to start a painting project, one that suited their interests and capacity. Her approach was process-oriented, natural and holistic. All of these ideas coincided well with my own training as a teacher. I worked closely with the activation staff who had already established an excellent

*Figure 14. Prepared working space. (photographed by K. Downie).*
painting program for their members. However, they wanted to expand their methods and resources and discover new ways to develop the direction of the existing art program. Minor refinements to the planning and physical layout of art space contributed to increased social interaction, greater collaboration among activation staff and the visual representation of new voices among the membership. One simple change that was made at the outset of the classes that I led, after observing several sessions first, was to create what Montessori called a microsphere for each of the participants. This was achieved through providing each learner with a masonite board upon which paper was placed and taped so as to create a frame around the picture plane. The board is similar to a placemat in size and functions as a smooth and portable painting surface that can be adjusted easily in response to the needs of the painter. All of the required painting materials including a paint-set, two or three brushes of various sizes, water and a sponge, are placed within easy reach of each participant. Such a set-up is not only visually appealing and inviting, it explicitly declares that there is a prepared space at the table for each participant. Organizing these items in a simple and non-cluttered fashion also sets the tone for a failure-free and satisfying experience.

**Arts-Based Methods of Teaching Adults with Alzheimer’s**

Engaging in arts-based teaching methods is not simply a way to reproduce or create a product. It is a method that employs the right hemisphere of the brain, sparking alternative ways of thinking and working, either independently or in a small group setting. Furthermore, arts-based methods support collaborative and social interaction in which the student and learner both direct the action of the creative work through engagement and response – reciprocity. In this way, the goals of a bi-directional,
collaborative and shared learning are best supported by creative art projects that are flexible, failure-free, exploratory in nature and expressive.

It proved essential to engage cognitive processes throughout the work, asking participants, even those who used minimal verbal language, what they “thought” about the work that they had created. I often asked my students to advise me of what they thought should happen next. For example, a participant might ask, “What should I do now?” In response to this question, I suggest that the person look at their work, while I hold it a short distance away at eye-level. I then ask them, “What do you think the composition needs?” More often than not, the person will point to an area of the canvas and say, “It needs something here (pointing to the area).” According to Dijkstra\textsuperscript{130} remote memories are more easily accessed by people with Alzheimer’s, permitting continued access to “more generic semantic memory.”\textsuperscript{131} Procedural memory, on the other hand, is established through over-learned, or practiced actions and remembered by the body. The advisory capacity of individuals is a function of implicit memory, which is attained coincidentally and in tandem with lived experience. Likes and dislikes are not remembered explicitly in the way one might memorize a poem, but rather embodied through the experience of exposure to a food, a colour or a type of music. Seeking advice from a person with Alzheimer’s engages this aspect of memory and fulfills a role for the person as well, who is seen as possessing valuable and useful information. In designing a wall mural for the centre, I worked with several of the day program members to come up with ideas and a design that would reflect their interests. One of

\textsuperscript{130} (Dijkstra, 2006).
\textsuperscript{131} (Dijkstra, 2006, p. 358).
these individuals who had Lewy body dementia – a complication of Parkinson’s disease – responded very positively when I asked him for some ideas related to themes, motifs and patterns. He explained that as a civil engineer he had traveled extensively and had purchased carpets and books on Far-Eastern patterns and “motifs.” He said that he would like to include these in the mural. Despite his loss of memory, he was able to make quite a few connections in response to a simple and direct question.

Sharing as a Claim to Personhood

Throughout this project each participant has developed and communicated a unique, distinct and expressive style through the creation of their artistic work. This achievement alone could not have happened had I decided to engage this group in crafting a finished product using prescribed processes and techniques. In using an open-ended, inductive approach, I was able to shape the painting process by employing suitable techniques, resources and sources of inspiration in response to the needs and individual goals of each participant. In this way a unique and continuous dialogue was established and maintained throughout the 12-week study with each person. This approach, clearly distinguished from a step-by-step teaching model, appealed to and apprehended the attention and imagination of the study participants.

Very clear evidence of this was seen in the work of Theresa who initially painted in response to images found in books and magazines or very rarely from pictures that I drew for her. As the program progressed, she became more interested in the vibrant images that existed in her mind. In time she strictly painted images of an inner landscape that continued to evolve. In more recent weeks, long after the conclusion of
the study, she has demonstrated a clear mastery of the medium. She paints in a cohesive way, using vibrant combinations of colour and textures that fully exploit the delicate, colourful and flowing properties of watercolour. She has gained a confidence with the process — which is open-ended, failure-free and supportive — enabling her to give shape to her inner thoughts feelings and ideas.

Lowell also exhibits a strong impulse toward the expression of his life-long experiences related to family, friends and travel. He approaches each class with a desire to reflect upon his work from the previous session, aiming to establish a link between these prior artworks and the imagery that he anticipates and prepares to create during each new class.

*Lowell brought an array of resources that might serve to inspire — so, much like an artist — a Matisse booklet, another from an Egyptian exhibit, a beautiful postcard and catalogue of sculpture that he loves. He also brought an article about spiders — we used this to inform a new sketch — which he painted of two spiders. ‘What Should We do Now,’ I think he titled it. Initially he named it ‘Don’t Bite Me’ — but after a while he said — ‘that’s not me,’ as if to say, I’m not afraid of life! He renamed the painting ‘Which Way Shall We Go?’*

Lowell is a very positive man, who continues to take time to encourage others and praise their work, particularly when they are self-critical and sometimes disparaging of their efforts. “*Lowell commented on Frances’ expression today, which he said seemed much happier.*” In his own work he paints very freely and then takes a careful
look to identify all of the images that he sees within the composition. One day Lowell asked me how my thesis was coming along. I was very open with him in my response, telling him about the emergence of reciprocity as an important theme for my thesis work. He asked me detailed questions in order to gain a better understanding of my words, and I spoke further about the way in which he and I could help one another – I, with painting and he, with his insights into the process of research. “I will think about that,” he said. After our discussion he began painting, creating a two-headed snake. We talked about the serpentine shape of his brush strokes and the eyes that seemed to identify each end as a head. I thought to myself, that this image represented an internalization of the discussion we had immediately before Lowell began to paint. It seemed that he was processing the notion of two people working together.

**Qualities of Art**

Some would say that the artworks created by the participants of this study are simplistic, childlike expressions that lack the qualities often associated with fine art imagery, thereby disproving the success of the painting lessons. Notions of artistry can be deceiving and need to be questioned and considered. I am always frustrated by the dissatisfied musings of art gallery patrons who claim, “I could do that,” while observing works by artists such as Rothko or Pollock. In fact, reproducing these abstract master works is a serious challenge that few may accomplish. This is because the image is realized through more than technical skill and knowledge of the technicalities of colour, light and form. Moreover these artists’ works are so powerful and elusive because they emerged out of the profound, if not mysterious, yearning to seek out, reveal and express that which defies words. This imperative troubles and compels the artist to explore
openly and freely, thus silencing the weight of fear. The implementation of art classes intended for people with Alzheimer’s works so well because of the presence and openness that resides within these individuals. Furthermore, I am so interested in each and every painting created by my participants because the production of these works represents far more than the objects themselves.

Each work must be viewed within the broad context of the person who created the image. These were created through a process that was creative, open-ended, evocative, expressive of self and risky. One afternoon I was with Lowell as he painted. I was encouraging to make a mark on a fresh white piece of watercolour paper. While he was ready to go – his paintbrush was saturated with a rich blue colour – he was hesitant. I reminded him that he had nothing to lose. This is a sentiment that art instructors hold and readily espouse to their students as a form of prompt, to suggest that no harm will be done, and that options always remain open after you have made your mark. Lowell looked at me with a serious eye and replied, “We all have something to lose.” He was so right, and I was struck by my lack of thought. Of course, we all have something to lose, particularly my dear friends with Alzheimer’s. Being prompted by an art teacher to make a mark or gesture with paint is equivalent to standing at a precipice. It can be very fearful because we know that such a mark will reveal who we are. Thus, art making, even in a risk-free setting is a risky affair. Most of the participants in these classes were willing to take the risk, not all however.
Chapter 9
Reflections

Creating artworks as a mode of communication and expression is always a risky
demand, because artful and artistic processes are often unpredictable. In working
with a group of people with Alzheimer’s, I was continually mindful of aspects of the
process that might be overwhelming or unsettling for my participants. However, as the
process evolved it became apparent that my participants were lively, capable and eager
to paint, learn and develop their voices as painters. I am forever changed by their
teachings of insight, presence and patience.

This group of participants collaborated with me throughout the study period as
they learned how to paint with watercolours. All of the participants established
familiarity with the materials and some of the processes and techniques used in painting.
These included wetting paper with a sponge as preparation for a wet-on-wet paint
application; differentiating and mixing the colours of the paint palette; and applying the
colour to paper. Many free-form and still-life compositions were created throughout the
process. Some of the participants developed proficient skills in copying art imagery
taken from books and/or creating figurative compositions from their imagination. All of
the participants required a different level of support for each stage of the process; most
developed a degree of comfort and fluency with the materials and processes; and 5 of the
original 10 participants still continue to paint on a weekly basis, demonstrating
improvement in overall visual and verbal communication.
At the conclusion of the study I identified a procession of stages that resulted from the work that developed throughout the study. This continuum has a scope of 10 core aspects that range from refusal to reflection and sharing. The participants who accomplished the most in terms of time commitment and cognitive, procedural, affective and artistic development moved through each of the identified stages. These individuals derived great satisfaction from the classes and demonstrated a clear ability to commit to the weekly painting sessions. As well, they consistently embodied a positive outlook in relation to painting and a willingness to work with others in the group. One of the participants – in the most progressed stage of Alzheimer’s relative to the other participants – showed improvements in verbal expression and ability to focus and function with minimal intervention and support.

**Relying Upon Others for Care**

The work that I do with people with Alzheimer’s is so joyful. It is mutually fulfilling and full of purpose. When I mention this to family caregivers who have provided care or continue to care for a mother or father with Alzheimer’s or Parkinson related dementia, I often receive a mixed response. I recognize the pain, frustration and feelings of longing that the person holds for the parent whom they have missed or long ago said goodbye. It is often very painful to care for a family member, particularly a parent, who is losing cognitive capacity, memory and connections with self and other. We forever compare the person who once was with that of a person who appears to be less of an individual. For outsiders however, no such comparison exists, enabling acceptance and opportunities to share in other satisfying ways. It is important that those
who have family members with dementia rely heavily and without guilt upon the resources of others.

**Need for Innovative Educational Programs**

The current generation of ageing ‘boomers’, coupled with lower birth rates following the ‘baby boom’ which produced a diminutive younger cohort (the caregivers of the future), contributes further to the looming global health crisis of the 21st century. In tandem with the urgent need to provide educational, clinical, social and economic support to people with dementia, is the need to foster and develop educational models that (a) enhance and promote professional learning related to the complex issues associated with AD and related dementia (ADRD), and (b) facilitate learning that intersects with and influences the mainstream spectrum of care provided through medical and social avenues. The development of educational models particularly those informed by the arts, offer opportunities for enriched learning and inter-professional and inter-cultural development within circles of care for people with dementia. “Educational institutions play a major role in facilitating the necessary social adaptation to the challenge of global aging and the related changing social and health needs.”

The results of this research study demonstrate personal, relational and social benefits for people with Alzheimer’s at the levels of personal growth, inter-personal relationships and community. Recognizing and celebrating personal growth in people with Alzheimer’s is a significant, if not monumental, outcome of this study, as it challenges many assumptions about the progressive diminishment of personality,

---

132 (Dartiques, 2004).
133 (Hyman, 1979, as cited in Lowenstein, 2009, p.707).
The benefits of arts educational programs for people with Alzheimer’s are numerous and influential as they impact personal, relational and social spheres. In this case, a person with Alzheimer’s might say, “Would you repeat the last part of what you just said again?” Lowell, one of my regular painting students, has said this to me from time to time in response to questions that I have asked him. I can see that he is struggling to make sense of my words, and I wait quietly. If the meaning of each of my words do not fall and click into place like coins dropped into a coin sorter, he will stop and ask me to repeat myself. And so I do, after a flood of panic rushes through my body in a swoosh that I am certain everyone else in the room can feel, as I think to myself, “What did I just say?” And so we go along, moment-by-moment, constantly listening and adjusting to the cadence of the other, while mixing paint and creating imagery.

**The Essence of the work and future direction**

This work begins to describe the life affirming and transformational journey that our group shared. The underlying assumption is that people with Alzheimer's are people first who retain their sense of personhood, identity and longing to connect and communicate throughout the progression of their disease. Despite cognitive decline, the
soul and the heart continue to burn as intense flames fuelled, not only by sensory perceptions, but also by a profound sense of knowing.

With this in mind, I began to view the members of the program that I worked with closely through the lens of their personal and professional life history. All of these individuals had interesting stories to tell about past and present lives and all, both men and women, held professional careers in science, medicine and the arts. Each was a highly proficient professional who had served their community and family in many important ways. It was not until my own sense of humility was fully restored that I was able to view these individuals in a more human and connected way. Growing old and living with dementia are two acts of courage that make visible the troubling space between our perceived and assumed sense of completeness (cognitively, physically, spiritually) and the countless and inevitable forms of frailty that we witness in others as they grow older.

Yet, despite the neurochemical changes prompted by Alzheimer’s, learning may continue to occur on cognitive, procedural and spiritual levels. While cognition in those with dementia diminishes in response to the growth of plaques and tangles throughout the brain, aspects of the brain’s architecture remain intact and vital. Cognitive exercise and continued exposure to formal learning opportunities impact the neurochemistry of the brain\textsuperscript{134} and may contribute to plateaus,\textsuperscript{135} or extended periods of stability, in persons with dementia. Those who work closely with people in the later stages of

\textsuperscript{134} (Doidge, 2007).
\textsuperscript{135} (Bozoki, 2009, Graboys, 2008).
dementia attest to evidence of insight and knowledge within the person.\textsuperscript{136} Intimacy, touch, feelings of closeness and emotion evoke moments of profound connection and knowledge shared between the person and their caregivers (Kitwood, 1997).

\textsuperscript{136} See Jean Tyler’s The Diminished mind, 1993
Figure 15. Rooster and flame. Painted by Lowell. (photographed by K, Downie).
Figure 16. Lowell (photographed by K. Downie).
References


Appendix A

The Neurobiology of Alzheimer’s Disease

Alzheimer’s disease is commonly viewed as an affliction of old age, however rising incidence of this neurodegenerative disease worldwide, and more frequent occurrence of early-onset Alzheimer’s draw attention to the significant social and economic impact of this disease and others which cause dementia. As the leading cause of dementia, Alzheimer’s strikes one-in-ten of those over the age of 60 and one-in-five of those over the age of 80. Furthermore, prevalence of this disease promises only to rise, as global populations and life expectancy within the developed world increase.

Chemical changes within the brain alter the structure and function of neurons in persons with Alzheimer’s. Microscopic neurofibrillary tangles (NFTs) infiltrate axons, the nerve fibres that extend from neural cells along pathways in the brain and spinal cord, and amyloid plaques permeate the cellular structures of grey and white matter targeting the frontal, temporal and parietal lobes of the brain. These plaques and tangles slow and gradually block the flow of information that normally travels between neurons as they fire. When breaches in the brain’s complex network of neurons, axons and synapses occur, perceptions and organized thinking patterns become obscured. Thus, the capacity of the mind to think and communicate clearly is altered, limiting the brain’s normal function. Indeed, Alzheimer’s presents many tragic consequences for those who live with this neurodegenerative disease and for those closest among family

137 (Alloul, 1995).
138 (Allen & Dawborn, 2007; Xiang et al., 2009).
139 (Allen & Dawborn, 2007).
and friends. Without access to memory, orientation to time and space and the ability to synthesize complex happenings within and without the self, the gradual diminishment of identity and self-determination takes hold limiting independent function. It stands to reason that in this case the capacity to learn must also be curtailed.
Appendix B
Differentiating Art and Craft

The convergence of friends, family or colleagues around a table is familiar and evocative, as it immediately brings to mind the potency of intimate gatherings. These may evoke festive, poignant and even dissonant associations for a person invited to the kitchen table\textsuperscript{140} where all manner of life events take place, bringing with it the potential of discovery and the risk of the unpredictable. Much stands to be learned amid the stories told around the table setting while savouring a glass of wine, a meal prepared with love and expectation, or over a quick cup of tea. The difference between the making of artistic works and crafting objects may be akin to that which distinguishes the preparation of a tried and true recipe and one that is improvised. Familiar dishes that require precise attention to weights and measures and strict adherence to the prescriptive steps that yield a certain product contrast those made on the spot, improvised on the basis of available ingredients found on hand. This latter method employs imagination, intuitive flare and a sense of daring, as the process may just as easily result in failure.

At the crux of differentiating the making of art\textsuperscript{141} from the making of craft are three concerns: the intention of the work to be product oriented or process oriented; the method of creation, which is determined by the intention (prescriptive or intuitive); and finally the purpose or motivation for creating the work. Is the work being produced for profit or is it being made to fulfill a deeper purpose of expression?

\textsuperscript{140}“The kitchen table” makes reference to the academy and the kitchen table,
\textsuperscript{141}In this case the making of art refers to the visual arts
The making of art pieces that are product-oriented require and certainly engage a variety of skills, practices and imaginative qualities from those made through creative process-oriented methods. In the case of the latter, the process determines the nature of the work. This means that in making an object, the artist must delve deeply into unconscious streams of self to reflect upon and respond to the work as it manifests. Such a process can be both liberating, as well as anxiety making, because the final outcome of the work is unknown. In this way, the artist is involved in a risk-taking, albeit expressive, venture of discovery. Thus product-oriented and process-oriented works respectively utilize prescriptive or intuitive methods to actualize art pieces. While prescriptive methods are necessary and certainly useful within the grand scheme of artistry, if relied upon solely these procedures may easily curtail the imaginative turn of the artist who is concerned with representing personal themes and ideas that are not so easily expressed otherwise. Finally, the motivation for creating objects and art pieces informs the quality and power of the work to transform both the artist and the spectator. The purpose of the artwork may be driven by financial imperatives, that is, as part of a viable business to produce (manufacture) and sell crafted pieces. Conversely, they may be the product of the artist who creates as an imperative of the soul, which constantly seeks to interpret the world and make meaning, regardless of remuneration. Sometimes the purpose of the artisan and that of the artist become entwined as a powerful and provocative force. British potter Bernard Leach was the embodiment of such an artist who at once perfected his production of pottery into a form now well-known and respected in Cornwall, England, while imbuing his forms with both mastery and a rich spiritual essence that was his voice. His pieces are transcendent, yet, highly identified and recognizable by their established forms and practiced patterns. Leach’s pots
are resounding because they embody the artist’s search for a purity of form found within humanity.

Understanding the distinction between product- and process-oriented methods is an important one to discern, particularly when considering the design and implementation of educational programs designed for people with special needs stemming from communication disorders. This is because these individuals strive to connect and communicate in profound ways. Limiting options and denying opportunities for engagement aimed at facilitating communication and expression, short-changes those who have so much to gain from creative, process-oriented methods of creating artworks. My point is not to suggest that one art form is better than the other, but rather to state that their differences lend to or detract from the needs, processes and purposes of engaging participants in creative work, particularly when there is the potential for therapeutic outcomes.