

**THE MEMORY BRIDGE TRAINING RETREATS:
AN ETHNOGRAPHIC EVALUATION**

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ACKNOWLEDGMENTS

Thanks to my skilled and patient transcribers,
Kathleen Carspecken, Sunil Carspecken and Michelle Collard.

And thanks to Indiana University's Faculty Writing Group for providing a
weekly space and time to work on this report.

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INTRODUCTION: THE MEMORY BRIDGE TRAINING RETREATS FOR 2015 AND 2016

That is what struck me; that Michael was talking about what Alzheimer's was teaching *us*. We don't have to figure out what to do with them. It is forcing us to figure out where we have come to and how we define humanity and what we are going to do with ourselves. It is really distilling down this notion of what it means to be human.

Sarah 2015

For five consecutive summers in Southern Indiana, groups of a dozen or so people gathered for training retreats run by a non-profit organization called Memory Bridge. Most of those attending came from within the United States. Some came from as far away as Canada, Europe, even Australia. All were involved with dementia care in one form or another, and they wanted to deepen or reinforce their understanding and to improve their practice. In this report I will provide an ethnographic portrait of the trainings in 2015 and 2016, with a focus on the educational approach. I will be looking at how and whether the participants perceived it as making a difference in their work, and I will also be looking for Memory Bridge's unique contributions to the field. I will conclude by discussing its broader applications for dementia-care pedagogy as a whole.

Memory Bridge's overall purpose is, according to its website, "to create a global community of people who, like us, are learning to listen to people with dementia for what

they have to teach us about our own humanity.” Education, community building and advocacy are some of the strategies it uses to meet this broader goal, and the summer sessions combined these. They each lasted for five days, and the participants stayed on site for that time. I have chosen to refer to them as “training retreats,” as this is the phrase used by the organization online. However, Michael Verde, who is the founder and facilitator, sees both words as inadequate. He elaborates; “I don’t think there’s any training involved. There’s got to be a better word. The “training retreat” is a kind of compromise. We are retreating but it’s not about us.” As I describe his vision for Memory Bridge I will also explain his ambivalence about these terms. But first I will look at dementia and dementia care within the United States, and offer some context for the organization’s work.

Memory Bridge in Context: Dementia Care in the United States

Dementia is a growing, much-publicized and much-measured phenomenon. In the United States there are 5.7 million with this diagnosis in 2018. Over sixteen million people work as informal, unpaid care partners for them. Of these, sixty nine percent have provided care for at least a year, and more than thirty nine percent have been providing care for four or more years.¹ Family caregivers for the cognitively frail are themselves vulnerable to depression, anxiety and ill health.²

While it is hard to accurately quantify the emotional needs of people with dementia, recent research has found an inverse relationship between satisfying social

¹ Alzheimer’s Association Factsheet, March 2017 Viewed July 20th 2017.

² See, for example Schutz and O’Brien, 2015 and Cooper, Balamarall and Livingston, 2007

interactions and this label³ - that is, the more positive relationships a person has, the less likely it is that they will receive this diagnosis. This suggests the value of attention, interaction and listening as preventive measures. Recent research also points to respectful and trusting interpersonal relationships as an essential feature of effective dementia care.⁴ For Michael,⁵ as for other theorists and advocates, social interaction with this population is not only a means to stem the progress of Alzheimer's but is a good in itself. Empathetic attention is valuable for elders and for other people diagnosed with cognitive disabilities not because it will prevent or cure a "disease" but because connection is an inherently desirable feature of life. "Everybody needs to matter" Michael says, "And everybody needs to belong."

Memory Bridge's philosophy is distinct from a traditional medical approach to dementia, but it has much in common with another strand of memory care, which draws on the humanistic psychology of Carl Rogers⁶. The best known initiators of this approach are Naomi Feil and Tom Kitwood. Feil worked as a social worker in the 1960s and came to appreciate the value of empathy, listening and validating elders' experiences, whether or not these conformed to "objective" reality. She originally published *Validation: The Feil Method*, in 1982 and later wrote *The Validation Breakthrough*.⁷ Feil has been an inspiration to Michael (among others) and has led workshops at Memory Bridge retreats. Kitwood - a psychologist and former priest from England - regarded the ill-being experienced by cognitively frail elders as a result of their being treated as "nonpersons."

³ See, for example, Fratiglioni, Wang, Ericsson, & Winblad, 2000

⁴ See Fazio, Pace, Flinner & Kallmyer, 2018. See also Brooker, 2006 and 2004, Fazio 2008, and Kitwood, 1992

⁵ I will use first names for all participants and organizers throughout this evaluation, unless they express a preference for their last names or for pseudonyms.

⁶ Rogers, 1961

⁷ Feil, 2002

According to Kitwood personhood is ‘a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust’.⁸ His work influenced dementia support around the world and is fundamental to what is usually called “person centered care.”

Later authors added new elements or processes to person centered care – like the VIPS model,⁹ and the Senses Framework.¹⁰ The Alzheimer’s Association includes a person centered focus as “the core of quality care” in its 2018 website.¹¹ This approach was also instrumental in the various institutions developed by the Culture Change movement, which attempted to create home-like environments as well as respectful relationships. It included the Eden Alternative, Wellspring, and the Greenhouse/Small House projects. Person centered care has moved into mainstream thinking about dementia support, and was even noted as a Quality Strategy by the Centers for Medicare and Medicaid Service in 2016.

However there is a mismatch between theory and practice when it comes to aged care in the United States. In practice, people with dementia often report being ignored or infantilized.¹² Koren noted that the kind of transformation advocated by the Culture Change movement was limited by funding shortfalls, regulations and lack of nursing buy-in.¹³ Molony *et al* find that,

At present, many persons living with dementia do not receive person-centered assessment and care planning because of programmatic, organizational, and regulatory requirements and professional and provider

⁸ Kitwood, 1997

⁹ Brooker 2007

¹⁰ Nolan et al 2006

¹¹ <https://www.alz.org/dementia-care-practice-recommendations/> Website viewed April 2018.

¹² Bryden, 2016, Ellenbogen, 2012, Specht, Taylor and Bosser, 2009.

¹³ Koren, 2010

practices that reflect the needs of staff and settings, more than the needs of the person with dementia.

Another, (related), obstacle is the extremely high turnover among institutional care partners.¹⁴ Squires *et al* found high workloads, and lack of resources and autonomy to have the most deleterious effects on care workers' job satisfaction.¹⁵ Low pay is also an issue. Time pressure makes it difficult to enact person-centered care, even where this is an institutional or personal goal. Family carers have different, but equally serious challenges.¹⁶ Most person-centered approaches recognize the importance of respecting and supporting care partners as well as the cognitively frail. In practice this support is more of an ideal than a reality, as directors, supervisors, planners and trainers have to work within economic, political and institutional constraints.

Memory Bridge fits broadly into the person centered tradition, although Michael does not use this phrase. Through the retreats he contributed, (at least), two additional and unusual components to humanistic dementia care training. First, for five days the organizers set out to “feed the feeders,” both physically and emotionally. They covered board and lodging and immersed the participants in live-in, interactive experiences with one another, with the aim of forming communities. Second, Michael described people with dementia not just as equals but as mentors for the trainees. He argued that time with this population could be valuable for those of us who currently pass for “normal.” It exposes us to ways of being and communicating that go beyond the intellect.

The problems of putting effective care into practice in the mainstream medical

¹⁴ Castle, 2005; Mukamel et al., 2009.

¹⁵ Squires, Hoben, Linklater, Carleton, Graham, & Estabrooks, 2015

¹⁶ Schutz and O' Brien, 1995

system go beyond training approaches and point to a need for changes in policy and national economic priorities. These in turn require enough of a shift in public opinion to sway policy makers and politicians. This is a place where Memory Bridge could also make a difference. It advocates a sea change in the way we value elders, in the way we value cognitive diversity and in the way we value care. It has been working towards such an ideological change through media outreach - including two documentaries - and through its training sessions. The trainings offered a set of principles, and a way of looking at the world rather than a set of procedures.

Research Methods

Angela, who participated in the Memory Bridge training in 2015, took a photograph of chairs in a perfect circle in the room where her group had held its meetings. She told me that this image summed up the five-day experience for her, and that it had made the training a safe space: “The circle is encompassing. It’s equal... People are going to accept what you have to say.” I will use her vision of the circle - with participants as points around it - as an ideal for the research approach I employ in this report. I will incorporate the voice of every person who attended, along with my own impressions as an observer. Since this report is focused on Memory Bridge’s pedagogical approach, I shall look in particular at what people took from the various elements of the curriculum.

My background is in Inquiry Methodology rather than in a medical field; and while I teach both quantitative and qualitative methods I have specialized in qualitative research and in life stories. I know from experience that it is often challenging to defend the validity

of the latter methodologies in an era when a physical science model commands more respect, so I will describe my methods in some detail.

I conducted fifty-seven in-depth interviews. These included interviews with the two organizers – three with Michael Verde and one with Jane Harlan-Simmons – and interviews with all twenty-seven of the participants before the retreats, and with all but one of them afterwards. I talked by phone with the trainees and in person with the organizers. With the former group I drew on their application forms for a few lead-in questions to begin the first interviews. Other than that I took an open-ended, unstructured approach, following the thread of each interviewee’s own comments as much as possible so as to let their own priorities take precedence over my preconceptions. Most of the interviews lasted around an hour; a few were substantially longer and one or two were shorter. I also attended and observed many of the training program’s classes and activities in 2015 and 2016. Sometimes I took notes while sitting in the circle; more often I returned home and took notes afterwards on everything I could recall. I did not accompany the group on their daily visits to a nearby memory care unit because I did not have permission from the elders or staff at this institution to observe them or write about them. In 2016 I attended a drumming session there on the second to last day.

In the process of reading through the interview transcripts and my field notes, I compiled and drew out some common themes. I included striking stories, moments of intensity, and uncommon themes as well. It was often the unusual events, images and metaphors that stayed with me after an interview or observation, and often these were helpful in explaining the retreat experience or giving me a new perspective from which to explore it. The participants were articulate and engaging, and I had to make difficult

choices about including or leaving out quotes. After I had finished the first rough draft, I sent out the interview excerpts I had chosen to include and the other places in the text where they were mentioned by name, to ensure that I had represented them accurately. I provided a roughly equivalent amount of text space for each trainee rather than prioritizing one voice over another. The goal was to create a circle-like mosaic of experiences and insights from everyone who attended.

I will draw on the trainees' narratives of their lives before the retreat, their descriptions of the training, and the impressions, changes or other takeaways they came away with. I will be thorough, and will do my best to provide an honest reflection of what people said to me; which themes came up most frequently for example, and what participants said about the aspects of the training that made the strongest impressions. The emphasis will be on the trainees, but occasionally I will also refer back to my field notes to add my own perspectives from moments during the retreats. By including every perspective and by providing an equitable balance among these perspectives I aim to give the fullest portrait I can.

The overall approach will be ethnographic and descriptive rather than using a cause-effect or a pre and post-test model. For one thing the latter approach is impractical given the context. Each of the participants came from, and returned to, a different set of professional and personal positions and networks, where they related directly and indirectly with elders with dementia in different ways. This means it would be hard to measure the emotional impact of the training on the trainees, or on their relationships with elders, consistently. There are too many extraneous variables and conditions to consider for a quantitative model.

A second reason why I have not chosen to use a cause-effect model in this study, nor to rely heavily on quantitative or comparative data, is that I believe the report would lose rather than gain trustworthiness if I were to limit myself to generalized statements about these trainees, who seem to me to be unique and extraordinary. I had fairly long conversations with each participant, and heard histories and insights that were too memorable to flatten out into categories. There is not one trainee or organizer whom I don't remember with affection and a kind of awe.

Again I can benefit from the perspective of one of the participants as a reference point for explaining this aspect of the approach. In her first interview, Mary Jo frequently emphasized the importance of putting the focus on individual people in dementia care rather than generalized labels. She told me about the time when she was entrusting her father, who had a diagnosis of Alzheimer's, into a care facility. She had had thirty years of experience as a nursing home administrator, and she knew how medical terminology could get in the way of respectful relationships between elders and staff:

I didn't want him labeled.... I put pictures on display and said "Let me tell you about the man you are about to have the privilege of taking care of." I did not talk about diagnosis or medications.

I believe the more you know about an individual, their history, their life experiences - the more you can respect where they are coming from, who they really are.

She added,

In healthcare we have sadly removed the person as the focus....

Documentation gets carried throughout with that person, and that person is almost then doomed from anybody being able to realize who they really are.

In a similar spirit, I will capture more of the reality of the people and their experiences of the retreats through a circle of their own memories than I could do through a more conventional or standardized evaluation format.¹⁷ It is easier to imaginatively step into the shoes of people through their narratives than through a list of their formal positions, or through the quantifiable aspects of their lives (age, income level, years of education and the like.) I contend, like Mary Jo, that stories are closer to who human beings are. Hence I will often include fairly long quotes from participants, describing the narrative arcs of their experiences. At other times I will take short quotes from many people illustrating single themes.

A third reason for taking an ethnographic rather than a quantified approach is that when looking at concepts like loneliness, community and connection I will inevitably be exploring assumptions and values that both underlie and evade measurement. It seems simple enough on its face, for example, to argue for curing a disease. The rationale - alleviating suffering - is implied in the word "disease" itself, and we usually do not see the need to define physical suffering or ask why we should relieve it. It is taken as a given. Michael has run into more resistance for his emphasis on alleviating emotional suffering, and on alleviating the discomfort many people feel when interacting with people with dementia. He calls this discomfort *itself* "dis-ease", and sees it as a malady afflicting

¹⁷ I do not mean to disparage such an approach in any way - only to explain that it is inappropriate for this particular project. It would have great value for a larger, more practically focused study in which the participants came from and returned to more homogenous contexts.

mainstream society, although it has repercussions for the people who have been labeled as “diseased” as well. I will write more in later chapters about what he means by this. His focus is on improving the quality of connections between the cognitively frail and the other people in their lives. I will quote him here, because his words also show the difficulty – the oddness even – of assessing an experientially based training retreat in numerical terms. In one interview with me he described a series of letters he exchanged with a medical official. She challenged him to justify Memory Bridge’s approach by “proving that love matters”. He paraphrased his response to her thus:

I have no proof that love matters. The real question would be; prove that it matters that we live at all. I don’t need to prove to you that love matters.

You prove to me that anything else matters, without love. I don’t have to prove that I believe in my arm.

I’m saying that love matters. That’s all that Memory Bridge is claiming. It’s not claiming that it reverses people’s neurological condition. It’s not claiming that it makes them better. It’s claiming that for x number of minutes people experience love. It’s not therapeutic. Every second that a person experiences love, they’re not dying of loneliness. That’s the goal here. We’re bringing people to give attention to people. There are certain things that matter because we’re human. They matter. We know that they matter because we’re alive and we gravitate to them – they fulfill our desires.

Rather than claim proof or disproof of efficacy, then, I will describe the retreats with an emphasis on participants’ first-hand accounts. I will draw on what they told me of their journeys before, during and after the training.

An Overview of the Report

In the chapters that follow I will describe the various activities of the Memory Bridge training process through the words of participants and through my own field notes. I will go on to summarize how it supported or changed their perspectives (if at all) or made a difference to their work. Since interacting with people with dementia involves affect rather than a set of practical skills, I will look the ways the trainees talked about the relationships between themselves and elders or (depending on their positions) between themselves, the people they supervised and elders, before and after the retreat. In the final sections I will raise wider questions around care, around how people learn, emotionally as well as cognitively, and around what is worth learning. Can emotional engagement and ethical stances be taught or reinforced through teaching, and if so, how? What part does dementia itself play in this process? “Teaching”, like “training” is not an ideal word for what happens during a Memory Bridge retreat so I will use it with caution.

This report has five chapters. I will begin in Chapter One by looking at Memory Bridge’s vision and goals. In Chapter Two I will begin by describing the way the organizers selected participants. Then I will introduce the people who attended and will talk about the experiences, stories and attitudes they brought with them. All these things were educational resources in themselves, and made enormously important contributions to the retreats. In the third chapter I will describe the schedule and the other pedagogical components of the training retreats from the participants’ perspectives while adding a few of my own observations. In Chapter Four I will summarize the responses of the trainees to the experience as a whole – what they took from it, how they saw it as impacting their work, which activities or methods they made most use of, the memories of it that stayed with

them, and any thoughts they had about how future programs might be improved. Finally in the fifth chapter I will draw conclusions about where Memory Bridge fits and where it contrasts with existing forms of pedagogy, care and understandings of dementia; and I will summarize its broader contributions to human culture.

CHAPTER 1: MEMORY BRIDGE'S BEGINNINGS, ITS VISION AND SOME ASPECTS OF ITS PHILOSOPHY

Michael Verde founded Memory Bridge in 2004. Two of his grandparents had been diagnosed with dementia. He was particularly close to his Grandpa Leonard, a former laborer in the East Texas oilfields and, according to Michael, “a workman worthy of his hire.”¹⁸ Over a period of years, Michael listened to and recorded stories from the elder’s life, as his grandfather sat in an orange recliner with a spittoon close to hand. When Grandpa Leonard could no longer express himself through language, he enjoyed listening as the recordings were played back to him. There came a point, though, when he seemed not to recognize Michael at all. The relationship, Michael says, forced him to think about identity, and about the human elements of a person that remain when memories are lost.

Memory Bridge is focused on the lived experiences of cognitively frail elderly people themselves and their need for relationships within communities. To this extent it has much in common with person centered trainings. Michael describes the aim of the retreats in simple terms: “so people with dementia are less lonely.” Related to this is a secondary goal; ideally the training should also give care partners themselves a first hand and positive experience of being included in a community rather than a hierarchy. Another aspect of the training that stands out is Michael’s understanding of dementia, which flies in the face of some mainstream North American social norms.

As an illustration of this last point I will draw on a talk that I heard Michael give (with variations) at retreats in 2015, 2016 and 2017. He typically gave it in one of the first

¹⁸ Verde, 2018

few days, and it was called “Love is not Normal.” A central theme was the human tendency to look over our shoulders in any social situation for a real or imaginary “they” who are judging us. In interactions with people with dementia, he said, this does not work well. Being with a cognitively frail elder often requires acting in ways that this imagined “they” would not like and would not consider normal. He referred to a piece of film from *There is a Bridge*,¹⁹ his first documentary about Memory Bridge. It showed the therapist Naomi Feil with a lady called Gladys Wilson who had been diagnosed with advanced dementia and who had rarely spoken for a few years. In the film, Feil interacted with Wilson in ways that seemed not to consider any outside observer to the scene. She moved her hand rhythmically, mirroring Wilson’s movements, made consistent eye contact, touched her face, talked and sang songs using the language of a tradition and religion not her (Feil’s) own. She seemed fully in the moment. She risked rejection from Wilson and at the same time risked putting herself outside the bounds of “normal” behavior in the eyes of others. As this film demonstrates, connecting with an elder with dementia can push one into letting go of social norms and social fears.

Michael elaborated on this idea in my interviews with him. People may not always be aware, he said, of the way we monitor our own personas in relation to the various “theys” or internal supervisors in our mental landscapes, and it is often a process where we have limited choice. Our bodies may tense up unconsciously as we resist going into unusual forms of interaction. We feel awkward or ashamed. The sense of shame relates, according to Michael, to our positions in various social hierarchies; the obscure continuums whereby we judge ourselves as cool or not cool enough, good or not good enough, desirable or

¹⁹ Kay and Verde, 2007

powerful or respected or giving or smart or valuable or attractive or hardworking or successful or deserving or likeable or even acceptable. Although the “they” at any given moment may be imagined, the fear of failing “them” is real and has real consequences. Since people in advanced stages of dementia have lost much of their ability to manage their personas, meeting them where *they* are can bring us face to face with fear – the fear of letting our own persona management slip, and of being excluded from our own various social structures and communities.

Michael refers to the ego’s normal way of being in the world as “low grade anxiety,” so that even at the best of times it is not at peace.

Our ego’s anxiety is related to its fear that it’s not lovable, and so it has to *prove* that it’s lovable, and therefore there must be a scoreboard with which it proves that it passed... I would guess, from my own experience, that deep down it thinks that it’s disqualified because of flaws or mistakes – that it has participated in things, or thought things, that if other people knew it they would think you were weird, they would think you were something that they needed to get out of the community.

At first glance this could seem to put care partners in a hopeless bind – in order to alleviate others’ loneliness we must risk our own identities and our own precarious belonging in communities. But Michael believes that we can find sources of support other than social hierarchies. Elders with dementia have lost their places within such hierarchies and have also, in many cases, lost the ability to measure, rank and categorize others. Connecting with them, then, is “a wonderful space to get rid of all the things that aren’t absolutely transferable at the level of presence.” Connecting with others in the Memory

Bridge training groups is also designed to be an opportunity to experience community without hierarchy, and this ideal is built in to the way the training schedule is planned.

Michael wants to support the trainees in overcoming the awkwardness of interacting with cognitively frail older people. He explains a vicious cycle that can impede connections:

The number one reason people with dementia are dying of loneliness is because as their own capacities to communicate diminish, the chances of things being awkward if you reach out to them grows.

At both training retreats, participants used the phrase “crossing the valley of awkward” to describe their attempts at interaction. Michael drew on that metaphor to explain Memory Bridge’s vision:

Memory Bridge’s contribution is to create an environment where people are encouraged and supported as they go through the valley of awkward, and have, on the other side of that valley, an experience with a person with dementia that then becomes itself intrinsically motivating for similar experiences – and also bears living witness that there is something on the other side of awkward, that gives someone a practice experience of having gone successfully through awkward – with the idea that that person is no longer as incapacitated when they get to other valleys of awkward as they would have been before the Memory Bridge experience.

He went further, suggesting that not only was it possible to cross this valley but that “once they got to the other side they could have experiences that were anything but awkward. In fact they could have experiences that were absolutely ecstatically exhilarating.”

With these goals in mind, Memory Bridge invited participants who worked in dementia care or related fields to take part in a process that went beyond information and beyond an analytic grasp of Alzheimer's. The art of making connections with people, and especially people with cognitive differences, involves learning that is at least as much experiential, ethical and emotional as it is intellectual. Hence the curriculum included philosophical presentations on the importance of emotional and social connections, but it also included time with cognitively frail elders, it included storytelling and literature, it included singing and drumming, it included food and a quiet space, it included down time, it included meditation and it included mutual support and feedback among the circles of participants.

The non-cognitive aspects of the training were essential to Michael's vision, and in fact he described one of Memory Bridge's aims as being "to heal people from abstractions." In my interviews with him and in several of the talks he gave during the retreats, he emphasized the limitations of the intellect, which he associates with the ego. According to Michael the intellect truncates our perceptions of other people, reducing these to what can be generalized and measured. What can be measured can be ordered numerically. It is the intellect that categorizes and ranks and compares and evaluates people and it is the intellect that makes for social hierarchies. In the process it leaves out *particular* people with dementia.

Michael regards the body as a metaphor for everything human other than the intellect. And he sees community as a "body of bodies" or collective body. He links this idea to Victor and Edith Turner's concept of *communitas*.²⁰ This is a way of interacting,

²⁰ Turner, Victor, 1997, Turner, Edith, 2011

where people perceive themselves as subjects among subjects rather than subjects among objects: “It would be our way of no longer being *things* to each other.” Community is characterized by equality rather than by hierarchy. Hence Michael’s focus is on “being with” people with dementia rather than, (or as well as), “doing for” them. The former orientation involves recognition and reciprocity.

One of Michael’s core motivations for running the Memory Bridge trainings was that he wanted to show – on an experiential level – that community was possible. He aimed to support experiences of community between care partners and cognitively frail elders, and he also wanted to create a community experience among the trainees. This was part of what he meant by “feeding the feeders,” who would then go on, he hoped, to more effectively reduce loneliness among the people they worked or interacted with who had been diagnosed with dementia.

Michael regards communication as central to community. With people who are cognitively different, as with people who are very intimate with one another, communication takes forms other than direct, informative speech. And he sees this as an opportunity rather than a problem. Interacting with people who have neither mastery of language nor mastery of social norms provides a chance to communicate on a non-intellectual level and to experience community more deeply than we do in typical social life. They force us to be “at the level of presence” rather than at a level of abstraction or ideology. Similarly in very close relationships, he says, “Language has to do all kinds of neat things to keep up with our intimacy. Including be quiet.” Elders diagnosed with dementia use their bodies, and orient themselves through others’ non-verbal cues – tone of voice,

touch, movement, eye contact. They push us to recognize that it is not the content that is important in an interaction but the attempt to communicate itself.

He gave an example from his time with a lady called Lavallette who lived at a memory care unit. They were sitting together over a crossword puzzle, and she told Michael (without specifying the place or the person) that she went “down there” and talked to “him.” “Was he happy to hear this?” asked Michael. “Oh yes, he was!” she replied. He told me, “She used free floating pronouns. She was probably drawing on conversational templates where the episodic specificity evaporated.” He noted all the non-verbal behaviors, including his own, that were important in this conversation. If he had conveyed condescension, this would have shut down the connection. They interacted through tone of voice and gesture and eye contact as well as by drawing on the frame of a “normal” conversation. In Michael’s words, they made use of,

Any of the manifold ways where we demonstrate that we’re receiving someone with love, or whether we’re treating them instrumentally. We’re just communicating that all the time. Most everything we think of as a “behavior” is probably a communication. So I’m demonstrating to her that I’m sincerely interested in whatever it is. And there’s not even a topic. What she’s really trying to do is stay connected. So she’s essentially drawing on templates to keep me thinking that she’s worthy to talk to.

And then all of a sudden she pulls up her arm and shows me these bruises. Trying to talk about her arm. Her arm is a symbol of the degree to which I am interested in her.

At this point Michael took her hand. He moved his finger gently to the different bruises. He said, “It was almost like following a plot. The plot of her arm.”

Besides non-verbal communication, Michael considers stories, myths, poetry and metaphors to be ways of getting around the intellect and quieting the ego. He is a devoted reader of fiction and also a gifted storyteller. Stories, in his view, provide a parallel way of learning about the world – one which incorporates values and emotions more fully. As we will see in Chapter 3, the curriculum of the Memory Bridge retreats included discussions of literary fiction related to aging and care. The participants shared incidents from their own lives as well. Michael observed that we relate to a narrative differently than we relate to cognitive or factual information: “We relate empathetically. As if we were one.”

From the time that Memory Bridge began holding trainings in Bloomington, Jane Harlan Simmons helped Michael with the logistics and planning. Phil Stafford, a professor from Indiana University’s Center on Aging, was also involved in planning the first two sessions. Jane had been working with, and writing about, aged care for many years,²¹ yet she said she still learned a lot from the retreats. Like Michael she saw the value of using language in creative ways to convey Memory Bridge’s ideas, and she noted that they tended to bring in trainees who were, “very verbal and good at expressing themselves.” Their words often went beyond the cognitive level. She said,

²¹ Jane Harlan-Simmons is a Research Associate at the Indiana Institute’s Center for Disability and Community. Among other writings, she is co-author of Todd, Harlan-Simmons and Walker, “Promoting a Good Old Age”, 2007. She was also winner of the Jacob Piatt Dunn Jr Award in 2015 for her article, “The Sweetest Little Boy I Ever Knew: A Handmade History for an Institutional Life”, in *Traces*.

I'm learning from people who are using words to talk about things that aren't really expressible in words. There's a paradox. If it were just words it wouldn't mean anything. Behind the words, there's a reality there about what is important in life; that really has a kind of wider application or wider significance that goes beyond just people with dementia. It has the ability to change, I think, our society.

She gave the examples of two stories - one from Michael about his father and grandfather, one from a participant about a mistake she'd made in her own life, and which she regretted. The first story described an act of forgiveness, and, in the second case, by telling her story the storyteller experienced forgiveness from the group. This helped her to overcome a lingering sense of shame. Jane added,

You might say, "What does this have to do with people with dementia?"

But it seems to have a lot to do with it - the sense of acceptance and being willing to love someone who has made mistakes or is, as Michael puts it, cognitively imperfect, or people who have dementia. It does relate.

CHAPTER 2. “INGREDIENTS IN A CASSEROLE”: THE PEOPLE WHO CAME, AND WHAT THEY BROUGHT WITH THEM

The Selection Criteria

Michael Verde, Phil Stafford and Jane Harlan Simmons planned the first Memory Bridge Retreat in 2013. Michael had instigated a collaboration with Indiana University’s Center for Aging and Community, where Stafford is the Director. Stafford drew in Jane, and the three of them talked about logistics – for example how long the trainings were to be, where they would be held, how they would be financed and how many people should attend. One of the practical issues that needed addressing was how the trainees would be chosen. Jane set up the application procedures. Michael came up with some questions. He put a lot of careful thought into their design. One, for example, asked people to watch the video clip of Feil and Wilson that I referred to in Chapter 1, and to analyze their interaction.

The three planners worked together on selecting people for the first couple of years. During the two years when I was interviewing and observing, Michael and Jane worked on the selection process while Stafford was focusing more on other work at the Center. As word spread about the training, the number of applicants for each year grew. They had accommodations for about thirteen people for each session, but eighty people applied in 2015.

Once the applications were in, Michael and Jane each listed their participant choices separately and then conferred to see where the lists overlapped. Jane noted that

Michael had the final say but that her own input grew. Over the years she learned to identify people who would benefit from the training, contribute to it and make good use of it. The choice and combination of participants was crucial, because the retreats involved five long days where people were in close proximity to one another - eating, sharing rooms, getting up early and spending many hours together in circles or activities. Jane was conscious of the potential challenge this might pose, and said, "To me it seems like a recipe for some kind of conflict." But she added that it had worked remarkably well.

Michael and Jane expressed similar ideas about the criteria for accepting people into the program. These were the core qualities that they were looking for:

- They should show that they are emotionally invested in the application process. When I read through all the completed forms of those who were accepted for 2015 and 2016 I found the writing creative, insightful and self-reflective. It was also fairly lengthy, typically covering several pages.
- They should show enough affinity for Memory Bridge's approach that the training would make sense to them. They should demonstrate emotional maturity and "depth" (Jane's word). Michael said, "We stress *being with* as central because that would not necessarily resonate with everyone who's interested in things related to care and people with dementia. A sense that they understand "being with" as something other than being nice."
- They should show that they have specific plans as to how they would put what they learned from Memory Bridge into use - through their professional lives or through some other means. In other words they should be able to benefit people with dementia after they leave. Practically

speaking this tended to mean that applicants with professional positions were more likely to be chosen than lone care partners, although the latter were occasionally accepted if they had networks of activity and influence beyond their immediate circles.

- Finally the organizers tried to gather people with diverse positions and skill sets in aged care, and from diverse backgrounds and institutions. I will quote from an email from Jane on this point: “We try to achieve balance in each of the groupings, in terms of geographical origin, age, type of occupation, and (to the extent possible with our pool of predominately White, female applicants) gender and race. In other words, not evaluating people’s suitability just as individuals, but how will the individual fit in with, and provide diversity to, the group? We do look at the past experience and accomplishments of the applicants, even though we try to include younger people who might be just starting out in their careers.”
- Finally, Jane, who has a background in the arts, noted that she tended to be drawn to accepting people with artistic skills and approaches to dementia care.

The choices were difficult, and Michael worried that being turned away might feel like a rejection. This led the organizers to compose sensitively worded letters for the people who were not accepted.

The variety of people and perspectives and their ability to learn from, accept and appreciate one another were key components of the Memory Bridge trainings, because one of its core goals was to demonstrate community in action. A large majority of the

participants I interviewed after both the 2015 and 2016 retreats spoke positively about the combination of people and considered it an important part of why they benefitted from the program. Only one person suggested changes in the selection criteria, saying that more preference should be shown for people with a range of senior professional positions in dementia care, less preference for people with artistic expertise.

The Application Process

The application process required significant time and work. It had an early stage and a later stage. In the first stage, applicants needed to answer two questions. One was, “Please tell us why you are interested in attending this training?” The next was, “Please describe your understanding of the mission of Memory Bridge. How would a deeper understanding of Memory Bridge’s work enhance your own capacity and commitment to communicating with people with dementia?” Applicants sent Michael and Jane their responses to these questions along with two letters of reference from colleagues or supervisors and a Curriculum Vitae.

At this point Michael and Jane read through the applications and made their choices. Those who were accepted were sent the DVD of *There is a Bridge*, (which is the first of the two documentaries that Memory Bridge has produced.) They were then asked to respond to further questions about an interaction in the film between Naomi Feil and Gladys Wilson. Meanwhile, Jane communicated with people regularly – making an effort to set a welcoming tone before the session began. And Michael called each trainee once they had been accepted. All these interactions demanded thoughtfulness from the

applicants. They sparked thinking ahead of time about dementia care and they prepared the group for reflective conversation once they met in person.

Several trainees said that they found the application a valuable process – something that was educational in itself. Greg, for example, took *There is a Bridge* as an inspiration to try out new, non-verbal ways of communicating with his wife:

I thought the Memory Bridge film had a lot of profundities in it, which stirred my sense of what you might be able to do. And actually since then there've been quite a number of moments of real exchange. I think it's in part because of the influence on my practice, if you want to call it that, my way of being with her that the film suggested to me. Like mirroring, picking up the person's breath patterns and being with that. Cathy will purse her lips in a funny way and so I purse my lips in the same way. And I get a smile from her when I do that..You've got to smile, that's precious. I've always liked to make people laugh, but just getting her to smile is an hourly goal.

Greg gets some assistance in caring for his wife, Cathy, from paid helpers, and he also found the movie to be an effective resource for explaining the approach to care that he wanted them to take with her:

We watched the film together and talked about it. It was a good way of conveying the attitude I wanted them to pick up and absorb here with respect to Cathy-Care....They're hard-working women, you know, they're used to wanting to do the laundry and empty the dishwasher and mop the floors and all that stuff—the home care part. And I didn't want the activities

to take precedence over the being-with. They all got that, and they thought it was a great film and they wish they had had it in their training.

Like Greg, Maggie and Maeve tried new approaches in their work with elders as a result of watching the film. After seeing the interaction between Naomi Feil and Gladys Wilson, Maggie approached an elderly lady in the dining room at the nursing home where she was working, and put her face in her hands. The lady brightened up immediately:

Patients that are on the dementia floors are not allowed to leave; and a lot of them have what are called, "wander guards," which are wrist or ankle bracelets that prevent them from leaving unless they are signed out. If they are short staffed - which they always are - there is not an extra person to take them off their floor, so they are essentially stuck. If there is a way that I can relieve one of these patients from their insulating disease, I will try it.

And it was an amazing moment for me. I was just surprised at how well it would work. You could just visibly see the curtains come down around this one and she could see me with a new understanding.

Maeve shared the following experience, which was also inspired by the movie:

I had been working with a lady who had no language...and for a long time, I didn't do much with her. Then, actually after watching the Memory Bridge (documentary) - it had really inspired me - I had been doing some body-mind centering and some hands on; working with just touch. And I decided to go and sit with her. I sat with her and she moved, and moved her arm. So I touched her arm and she stretched it out. I then touched her foot and she

stretched it out. It was like a whole movement sequence emerged, and - it felt like she was aware that I was there. She was having a movement conversation with me.

It seemed like she was asleep but she wasn't. It really satisfied me... As I talk about it I feel the warmth and love in my heart and my body as I worked with her... I took a risk to do something different, and something happened.

The Participants

Gina had achieved extraordinary things as a volunteer Dementia Friends Champion and Founder & lead volunteer of the Exeter Dementia Action Alliance in England. She was the Pride of Devon Award winner for her voluntary work, and she was also a finalist for the Alzheimer's Society national Dementia Friendly awards for her Outstanding Contribution in that year. Both before and after the Memory Bridge retreat she worked very hard as an advocate for the social needs of the cognitively frail. Media outreach is only one part of her work, but by August of 2015 she had inspired numerous articles and a community radio show called 'Living better with dementia' which airs quarterly offering a platform to share innovative and good practice as well as giving a voice to people living with dementia and their care partners.

Besides this impressive history of activism and outreach, she clearly had an ability to resonate empathetically with people with dementia. She grew up in a family where feeling needy and being sensitive was viewed as a bad thing. As she has matured she has come to appreciate these qualities as strengths. She says, "Working in dementia taps into

my emotion and sensitivity – I identify what it might feel like to be that person with dementia, vulnerable and misunderstood.”

Yet she felt awed by the group she met at the retreat. She described some of her first thoughts:

Coming into the Memory Bridge retreat, there were eleven other people - what I perceived to be extremely academic, dynamic human beings. I thought, “My God, why did they choose me? And what is everyone going to be like, and how will I fit in?”

Like Gina, I had great admiration for the participants of both groups. In this section I will give a few examples of the life experiences they brought with them. I will begin by introducing them through rough demographics, bring in a few of their comments about learning from one another, and then move on to some of the incidents, encounters and relationships that led them to Memory Bridge.

Fourteen people attended the session in 2015 and thirteen in 2016. They ranged in age from their early twenties to their mid eighties with a slight majority (about eight in each group) in the middle of this range.²² There was one African American in 2015; all the other participants in these two years were White. Two men attended in 2016 and one in 2015, so the vast majority of attendees were women.

Most people came from the United States, but in 2015 there were two participants from Australia, one from England and one who was originally from Scotland (although she

²²I avoid asking people for their age when doing ethnographic research unless it is directly relevant for some reason. It feels impolite to me, (which is an indication of the youth orientation of our society), and pinpointing the exact number also seems unnecessary in this particular study.

now lives in Connecticut.) In 2016, three came from Australia, two from Germany (one of whom was living in Scotland at the time of the training) and one from England.

As for their working backgrounds, there were administrators and other employees at various levels in aged care facilities or wellness centers. There were also volunteers for non-profit organizations related to dementia. There were hospice workers, a consultant, a wellness supervisor, counselors, a professor of Nursing and an organizer for youth volunteers. There were dance therapists as well as people using other artistic modalities to communicate with (or about) people with dementia – like clowning, art appreciation, theater, stories and music. There were two students – one a medical student and one a post graduate student working on arts applications for mental health. Alongside these professional backgrounds, a number of participants had lived with or been in close relationship with family members who had been diagnosed with dementia. At least seven had been the primary unpaid care partners for relatives for some stretch of time. All these were involved in either professional, arts based, ministerial or volunteer activities with elders as well.

Learning from One Another

Most participants talked in interviews about learning from the other trainees in the program. This was a topic that emerged frequently and positively. As noted above, the organizers put a lot of thought into who was accepted, since a lot of learning came from interactions among the groups. Successful applicants were highly motivated, as shown by the care they demonstrated in their applications. Several travelled for long distances to get

to the retreat. Natalie left a small child for the week with her husband in Australia. Cheryl went into debt to pay for her journey - which was also from Australia.

Although the planned activities themselves enhanced a sense of community, participants also valued the simple chance to meet and be in prolonged contact with others who shared their interest in connecting respectfully with people with dementia and shared their affinity with Memory Bridge's goals. Maeve, for example, said, "It just made me feel I'm not alone." Pat also appreciated the chance to get to know people who shared her views on dementia:

I left there knowing—okay, I'm not the only one out here, you know? There are others who feel the same way. There are others who see this perspective. There are others who understand it outside of the traditional analytical way.

People also said that they valued the range in ages and the range of skills, backgrounds and experiences with dementia care. I will give a small sample here of the many positive comments participants made about the composition of their groups.

Greg said that the people "were all terrific resources themselves." As an educator, he was also conscious of the mutual learning that can come from a group relationship:

We were a bunch of strangers thrown in together in a somewhat stressful set of experiences. It was an opportunity to become intimates. That's a small group; that's a piece of pedagogy. We weren't three hundred people in an auditorium; we were twelve on a kind of journey together, so, I think that's a nice pedagogical structure.

Trainees talked about times when they'd learned from other trainees' skills, for example in the ways they interacted with elders. Cheryl said this about Debbie:

Debbie just, she owned Autumn Hills (the memory care unit). When she went there, you could see she'd spent her whole life working in that environment. (She was) in her element, and I felt really humbled that I was part of this incredibly inspiring group of people.

Stuart learned from watching Greg's interactions with the lady he was paired up with at Autumn Hills:

Greg, who would walk a million miles with that lady. Didn't know where she wanted to go, what she wanted to talk about, but he just - up and down the corridors. One minute she was happy and chatting like nobody's business, and the next she looked quite lost. And he just paced himself and went right along with it, and never gave her an "I'm finding this challenging" sort of look or anything like that. He had the patience of a saint. And obviously he's doing exactly the same thing with his wife. Pouring all that love out.

Sarah summed up this kind of learning:

It is not just my experiences with my buddy, but hearing everyone else's experiences with their buddies. Living a little bit through them - with them - because there were a lot of faces of dementia being presented... It made me feel like I have a lot to learn and a lot to do, but (I was) inspired and really grateful that there are people like those people that do what they do.

Emily noted that the group was “intergenerational, international, interdisciplinary”, and compared the combination of people to the “ingredients in a casserole”. She said,

I keep coming back to this word “generosity”. But I just felt it was a commitment that each individual brought forwards to the week and to our time together. Which I think was fostered beforehand through the nature of the application process.....

I think the true value is in identifying who goes on it.....I felt very, very privileged to have a seat in that circle. And I think that if that wasn't as carefully crafted, then I think the experience certainly wouldn't be anywhere near as powerful.

What the Participants Brought with Them

I have introduced this section by writing about the benefits the trainees found in meeting one another. To explain why this was so I will now give a few examples from their lives. I will begin with family experiences, then move on to volunteer and professional experiences, stories, insights and inspirations – in short, a variety of the resources that they carried with them to the training retreats.

Interviewing the people who came often proved an inspiration for me and I learned from the applicants’ perspectives before as well as after the training. They conveyed a great deal of respect for those with cognitive differences. To give a few examples (among many) from my first interviews with applicants, Pat and Brenda spoke of “elders on a journey,” and Brenda questioned the power imbalance in the whole idea of “taking care” of an elder

with dementia. Natalie said, “I want to see our dementia organizations be more active about involving people with dementia in their governance; on their committees, on their boards.” Jill described situations where elders with dementia had helped and supported her when she needed it. Sarah’s words, quoted at the beginning of the Introduction, were from her “before” interview.

As I mentioned above, almost everyone in both groups had some kind of professional position in dementia care. Because Carolyn was an unpaid family caregiver, she had a feeling of being set apart to some extent:

I was hoping for a retreat where I would meet people who understood where I was in my journey, and though I didn’t find precisely that, I did find empathy.

My experience was colored by the fact that I was one of only two participants who didn’t work directly in elder care. As a family caregiver, I naturally had a different perspective from the majority of the group who were there to incorporate Memory Bridge into their professions.

Her presence added a valuable perspective to the group, however. Pat noted that Memory Bridge gave her a sense of catharsis about her own past experiences as a lone caregiver, and she saw this echoed in Carolyn too. She said, “Listening to Carolyn was like listening to myself.” Molly said that because she had not had much first hand experience with dementia, she valued hearing from Pat and Carolyn. And Carolyn herself had very positive memories of the group:

I had an amazing time meeting all those fine people and hearing about the work they do. I admire everyone who participated. I loved laughing with them, singing with them, and hearing their stories. I was moved by the work being done all over the world to help people with dementia live meaningful lives. That's exactly what I want for my mother... I found hope in the kinds of programs Marigrace, Julia, and others are putting in place. I can't express how grateful I am for that experience....

The variety of people that I met - that was truly helpful. Just the idea, from Gina, that there's such a thing as Dementia Friendly communities. I appreciated the two people from hospice who were there - Jill and Sarah...Angela and Ryan, who are both in continuing care communities. My roommate, Maeve, doing dance therapy...

She talked about being inspired by the innovations she heard about - like the Dementia Café's that she heard about from Marigrace, and the strategies Jeanene used to teach care partners about the dementia experience.

Pat had worked as a minister, but, like Carolyn, her main experience with dementia had been in the role of primary caregiver to a parent. She had lived with her Dad for four years and had learned to communicate with him in non-verbal as well as verbal ways. Her time with him had clearly given her an ability to attune to other elders. Here she describes watching a lady during a drum session at one of Memory Bridge's visits to the memory care unit:

The woman that was sitting directly across from me, she was in what I call the Cadillac wheelchair, just like my dad. Where they're reared back most

of the time because of where they are in the journey - the jaw is slack. They might be sleeping, but they're not; they're listening. And then to see her wake up, open her eyes, tune in, and be a part of the drumming and everything. That was such a beautiful thing.

That's the same thing we've been trying to tell people with my dad. He may have his eyes closed, because Alzheimer's may be playing with that particular skill set. But he is also listening. He is also attuned more emotionally. So he senses people, senses their energy - whether they are genuine or not, whether or not they are just taking care of basic needs only, or actually trying to connect with him. And me having been with him for these four years plus - I see it immediately in his eyes, on his face.

Even someone with as much experience as Debbie found herself learning from being a primary caregiver in addition to having a professional position. Some years ago her father was diagnosed with mixed Alzheimer's and vascular dementia. She had to learn first hand about the role of family caregiver from being with him. She said that she found strengths she didn't know she had; and also noticed impatience in herself. She came to understand better why someone might have emotions like this when caring for a loved one.

She illustrated this point through a painful example. She was giving her Dad showers several times a week, and sometimes he resisted. One day she was in a hurry, under pressure from work. She said, "This needs to be done. There's no time for fighting." Her Dad said, "This really isn't about you is it?" He had tears in his eyes. She hugged him and apologized for losing perspective. He said, "I love you but sometimes I

just don't like you." Suddenly it was very clear to her how we so often discount the feelings, value and purposefulness of those living with dementia.

Her Dad had been an active man, who was an elder and teacher in his church, and who had studied every day. He was frustrated and angry about no longer being able to do these things. One day he said, "You just don't understand. It's like somebody else has the remote control and is flipping the channels and there's snow on the screen." It was a gift to her that he could explain what this felt like; and it was also a gift to be able to develop more empathy for other family caregivers.

Maeve combined experience as a primary caregiver with her professional experience as a dance therapist. Her mother had moved in with her and her husband and had lived with them for years. In the beginning the couple missed their space together. It was hard for the older woman to separate from her daughter at all, and Maeve had to learn to express her own needs:

I broke down crying, saying "I cannot do everything for you all the time."

So she comforted me and went off to daycare and she really enjoyed it.

Eventually Maeve's mother moved into a nursing home, and joined her daughter's dance therapy group there. In these sessions she displayed new aspects of her personality, and the two rebuilt their connection:

She was always laughing and happy. She loved the movement and music...

Our relationship started to turn around. The more she lost her language and ability the better our relationship became.

Maeve learned,

To be present, to be present where she was, to validate where she was, and not try to argue with her. And start to relate. As her disease progressed, having to hold on to the essence of who she was...

She would tell stories without words. So because of my history with her, I always knew the words. Sometimes she would be rambling, say some words, and sometimes they were not words but sounds... I would say, "Oh, that was when you were up the tree," and her eyes would light up and she would make certain sounds; so I would finish the story for her.

Greg had decades of experience with expeditionary learning, education in Rwanda and also with a program called ReServe, that matches skilled older professionals with educational projects and other volunteer work. Besides these contributions he had been the primary care partner for his wife for years, since her dementia diagnosis. In his first interview he expressed great sensitivity to her choices and moods. He appreciated Memory Bridge's emphasis on "being with" and had also found it valuable to communicate with her by "doing with" - based on his observations of her. His descriptions of their time together conveyed his attentiveness:

She roams the house and organizes things and lines things up... If there's a bunch of stuff on the desk or table, she'll order them. And I was noting that to some friends and they said "How about some building blocks?" So they sent us a little package of multicolored building blocks and I put them in a tray. Cathy and I can sit for hours and arrange and rearrange and put stuff back.

Sarah was a volunteer program coordinator at a hospice before coming to the Memory Bridge retreat in 2015. She had also taken on the role of primary caregiver for her partner's elderly mother, who developed dementia over the five years when she lived with Sarah. Sarah's account of their time together makes it clear how open she was to meeting the elder on her own terms:

There were a lot of things that were difficult being her live-in caregiver. But I just kind of fell in love.... I just felt like here was this living history. She had this incredible life story; and everybody does. And it was dying away in this little apartment. And I was struck by how little her family would visit with her - they were content to let other people take care of their mom, grandmother or aunt - and how impatient they were with her memory loss...

She told the same stories every day from her early life. So we are realizing that the process of life review - going over and over and over some of the life experiences, sifting through that and making sense of that - how important it was to have an audience.... So part of our role was this captive audience for what she wanted to tell us. That is the kind of thing that I find that family members don't have the patience for or maybe sometimes those stories are distorted a little bit.

I see this with family members of our hospice patients - that testing of memories. "Mom, get your facts straight" "You know you've told me that story before." "We did not live there, we lived here."

I was so struck by that. Just let her have the memories that she is having! I didn't understand why there was this strong need for her to remember things and see things the way *they* wanted her to.

Natalie was a senior administrator whose passion for elder care had been sparked by painful early memories of her grandmother:

My aunt - she meant well but she didn't understand the diagnosis of dementia. It was never clearly explained to her. I think she felt a lot of stigma about the diagnosis - that there would be something cognitively wrong with her mother. So my grandmother was regularly restrained.... It was very difficult. My Mum and I really wanted to do something about it, but if we tried to intervene we actually were cut off from seeing my grandmother, and we weren't even allowed to speak to her on the phone. We wouldn't even be allowed into the house....

Along with this feeling of helplessness, Natalie also remembered good connections with her grandmother:

We learned so much from her - her perseverance, how you could connect with her... That understanding that even if she didn't remember something that happened five seconds ago, that was something that was going into her mind. And it was making a difference, because we would hear about it a few days later. You had to be paying attention and connecting with her to understand.

She retained appreciation and compassion both for elders and for family care partners.

This ended by shaping her direction in life.

After all of that I decided, I know lives can be better for people with dementia - other people shouldn't have to go through what my grandmother went through. And it shouldn't be a situation for family members like my aunt - who don't understand there shouldn't be a stigma associated with this disease. There should be information for them.

Doctors should be explaining things better. There should be more direct support for people who are in the family.

That's where I got my start and my passion.

Some trainees, like Molly, Maggie, Emma, Emily and Marigrace were young but already passionate about elder care. Maggie, a medical student, had been inspired to a career in health partly by watching what happened to her grandfather. He had started out with chronic neck pain and had then suffered a string of botched treatments by physicians:

A frail elderly person and all the medical errors that could lead to their decline - you know he was a pretty textbook case. I think there was a lack of communication between his doctors and my dad. And I don't think there was a lot of consideration of palliation at that point. It was constantly "Let's fix this, and okay, now we have another problem so let's fix that."

He was on hospice for not very long. He had sepsis and pneumonia and then he developed bedsores. And I don't think it was communicated that my grandfather was in his last hours of his life. My dad was just very taken

aback when he died with him there. It has taken years for my dad to not feel responsible. I really did think he felt responsible.

I think that is a great example in my life of how not to die. I really prefer that no one in my family have to go through that. And I think there were a lot of steps along the way that could have been avoided. So it has been my inspiration.

Maggie heard about Memory Bridge through Molly, who trains and supervises young adults to work with elders, and who had attended the 2015 training retreat. Maggie said,

Molly had just come back with such a glowing review. She said, “Oh my God, it was amazing!” She told me about her buddy, and she showed me her bracelet, - her “There’s a bridge” bracelet that she has. It was very life changing for her, especially as a social worker in elder care. I respect Molly a lot.....

She is just a real gem and an excellent social worker. As part of the Alzheimer’s unit that I was doing with these young nurses in training, she had shown us the Memory Bridge video. We were watching it and then we had a Q & A... and I was just really interested in it. And so Molly said, “Maggie I think you would really love this.”

Molly and Maggie had both had important personal relationships with elders beyond their families. Molly had worked with homeless people through AmeriCorps, in a program where “being with” was emphasized over “doing for.” She had particularly valued her visits to a homebound poet, who was blind. She described this as “one of the best experiences of

my life,” and had kept a journal about the interactions. Maggie, too, had formed an important relationship while volunteering in a hospice:

I had this hospice patient through Tomkins County hospice care and this woman was suffering from COPD, which is a very anxiety producing disease. This woman is a special woman in my life and really why I went into medicine.... She was a musician and what she needed was somebody who would get her out of bed to go and play piano. And hold her to that expectation and not let her make excuses why she couldn't go. And just show up twice a week and go “Okay we are going to go and play piano now, are you ready?” And wait for her while she got dressed and wait for her to go to the piano....

I am a singer by training. So we would play and sing together and she had a book of songs that we would practice. And through that she would tell me about her whole life and her experiences with music.

Marigrace told me a story about an elder she had encountered at an Alzheimer's-friendly café in Seattle. It described a learning experience that was important to her, and also reflected her respectful, open perspective on dementia.

I was asking him one day about what he likes about going to the Alzheimer's café. He said, “I like it because I can be around persons with more progressed or advanced dementia than myself.” And that, in and of itself, struck me; because...I've had experiences of people saying, “I don't want have to look at that!” or “I don't want to think about what's beyond where I am right now”. It was very appealing to me, and eye-opening, to

hear him say, “Well, what I am doing is searching out and enjoying being around people that have more advanced Alzheimer’s than I do.”

And he continues to share this story with me about going to the café and greeting people. And greeting this one man who he said wasn’t responding verbally. He could recognize maybe the man didn’t have words or wasn’t at a place where he was responding verbally. His name is Richard²³. When Richard greeted him the guy did not respond. (He) ended up glaring or staring at Richard. So he sat down with him and...they ended up sitting there for multiple minutes and staring at each other. After a few minutes the guy reached out his finger to Richard and Richard reached out his finger. So they sat there for multiple minutes and just stared at each other, touching fingers, touching fore fingers.

When Richard tells me the story he says, “It is one of the deepest experiences of communication that I have experienced.”

She went on to talk more generally about why she likes interacting with elders:

It has allowed me to be creative and spontaneous and free. Because of how I feel when I am around older adults. That I do feel accepted. I feel like it is mutual. I look at people and, “Oh you are so unique,” and they reflect that back to me. I feel like there is an openness to try things and see how it goes.

Julia described several incidents where she had learned from cognitively frail elders.

At the time of the 2015 training she was a therapist who answered calls on a phone hotline.

²³ All names of elders other than family members in this report are pseudonyms.

Before that she had worked at a residential care center. She is highly empathetic, and one of her essential challenges was to stay present with people while not getting lost in trying to fix their pain. She handled this, in part, through a practice of mindfulness:

When I started my work at Brook Manor, (a pseudonym) there would be residents who were really in distress and would want to go home. (They were) asking me repeatedly to go home or for me to drive them home; or asking me every day, twenty times a day, to call them a taxi. Or crying and looking me in the eye and being so sad... I would join with them, and then I was sucked down into the depths and I could not get out.

I think the first step for me is always joining. We can join through a foundation of mindfulness and through empathy and being with and connecting. Where it was difficult for me was when I wanted them not to be sad anymore, I wanted to fix that. I would join with them all most too much... And in this situation I could not redirect.

She also described a memorable interaction where she learned about inclusion and forgiveness from an elder. She had been talking with a group of three women, where two of them could communicate verbally and the third could not:

The way that she spoke, you could get the emotional gist of it but it wasn't language other people could understand. So I found myself not addressing questions to her, as it was just easier in that moment to interact with the two higher functioning women. I was ignoring her. I would check in with her every few minutes, but I was really focusing attention on the (others)...and I was really with them.

So Sally, a couple of minutes later, got up from her chair and huffed off. I was like “Oh, wow” - she had just shown me that I had made an error here. And I was not giving my attention towards this woman. There was no reason that I should *not* have been giving her my attention in that moment. And I can be compassionate with myself and not beat myself up for that. But it was an important teaching...

I knew that she likely would not hold on to that memory. So later in the day I approached her and I apologized to her, and I wasn't specific. I just apologized, told her “I'm sorry.” And she was so tender with me. She touched my face, and it was a really beautiful moment of learning and joining and togetherness.

Another of the younger trainees, Emma, had both a mother and a grandmother who were diagnosed with dementia. Her mother - who had previously taken pride in her own professional achievements - went through a phase of denial and distancing from others when she was first diagnosed. This changed as she lost more intellectual abilities. Emma described the shift with great sensitivity:

The surprising thing with me was to encounter a lot of intimacy with her as she came face to face with the big challenge. The busyness of her life and the busyness of her mind got put aside for what was a very deep emotional challenge in life. And it has actually been an opportunity for us to come together and intimately share those views and hard times around the challenge. And I also think as things progressed it deepened our

relationship - having that heart based, energetic connection rather than relating to each other from our intellectual selves

Many trainees were already experts in empathetic dementia care. Jeanene, for example, was a Professor of Nursing. She had been writing on (as well as working with) this concept for many years, had published an article on Memory Bridge as early as 2008²⁴ and had continued to publish on the importance of conversation, listening and storytelling among cognitively frail elders as well as genuine emotional engagement²⁵. This last point has sometimes put her outside the mainstream in the environments where she works:

You are taught to keep a distance from your patients so that you don't get emotionally involved with them, especially when they are dealing with some type of diagnostic that is terminal. I always struggled with that because I will be the first person to admit that when I am taking care of somebody, they get all of me - well, I can't help it...

I have been given some of the toughest cases in my line of work. Cases where someone would come out of the room and say "I cannot get her to do anything, she is fighting me, she is pinching me, she is grabbing me, she is cussing at me, she is yelling at me and throwing things at me."

I am like, "Well let me go in and try." And my approach is always very humble, because I am entering her room on her terms. If I enter the room in that frame of mind and I look at them and I see that person for who they really are then I can actually sit next to them and whether through touch or

²⁴ Young-Mason, (Lindsey), 2008.

through singing to them or talking to them and seeing if they will respond. I have always found a way to get through.

Before coming to the Memory Bridge training, Mary Jo had established a residential institution with a focus on elders' dignity, uniqueness and contributions. She took enormous risks to do this work. It began with disillusion with mainstream dementia care. She acknowledged the good intentions of individual care partners, but saw them as poorly supported by the medical system.

For those who are truly committed with the heart, it breaks their heart. As a consultant, I have never seen the long term care industry in such low morale, low spirits, high, high, high turn over. It just breaks my heart, and that is why I can't be party to this.

Imagine, if you will, being assigned as a caregiver and your assignment is thirteen people. And how can you get thirteen people out of bed for breakfast or to a toilet? That is standard... These caregivers are just physically and emotionally burned out.

I have been a nursing home administrator and director of assisted living and I worked in the formal long term care settings for the last thirty years. Two years ago. I decided to say "No, I don't want to do this anymore." I've got to go back and design my own facility and create my own learning awareness...I want them to see it lived out where they can witness the beauty of wellbeing based on interactions and relationships.

She explained why she was willing to risk leaving job security behind to establish an institution of her own, Stone Lodge:

I didn't want my own spirit to be broken.... I said to myself I am not going to conform, because I have these beliefs, these convictions. I am going to go in a different direction and try to figure out how to further strengthen and enhance my beliefs in a way that I can make a difference for others....

I left my job, with a salary of \$100,000, to nothing. To nothing....

I cashed in my entire retirement savings to purchase a vacant church. For Stone Lodge, we repurposed this church to look like an up north lodge or a vacation destination, a resort. Absolutely nothing clinical, institutional about it at all... Our focus is on wellness and person centered care, not on disease and diagnosis.

In her interview, Mary Jo gave me several examples of how Stone Lodge works in practice.

She told the story of a man who had recently come to live there:

I have a Veteran who has lived in the VA hospital down in Indiana for the last year in a four-bed ward. And they described this man as like a monster to me... I *want* the ones that nobody will take because I believe our people are inaccurately described. I believe that we are so stuck on the clinical documentation and the labels that we are totally creating a false picture of the true person.

And this man has lived here for four weeks now - and zero, *zero*, attempts and "behaviors"... They said, "He will be trying to get out the doors; he will

throw things through windows”... He has not done anything, as so fearfully warned.

This man is so beautiful; he is such a gem.... He was simply bored out of his mind, with no purpose, no meaning in his life. So of course he is going to act out, because he is trying to communicate this unmet need of “I need to be doing something.” (Now) this man has jobs all day long. He is out sweeping the patio with me and cleaning off the patio furniture and he is just busy, busy... He is on Cloud Nine...It is amazing to witness how you can make such a difference...

He gets wrongly labeled because there was no activity for him and that is why I go back to “Maybe we are the ones creating or causing (this).” And then they get labeled and then, unfortunately, even medicated because of our inaccurate descriptions.

Like Debbie and Maeve, Mary Jo had experience as a family caregiver as well as a professional one. In the Introduction I quoted her as someone who wanted her father treated as a person rather than a label. He was one of the first residents in Stone Lodge, and she talked about her history with him. This narrative also reflects her appreciation for dementia as a gift:

When your profession turns deeply personal like that of caring for your own parent, it takes on a whole new meaning and an entirely new perspective.... My husband was diagnosed with cancer at twenty-six, and he had a brain tumor. And every day my dad drove him to radiation therapy at the hospital, because I couldn't - I had two little babies at home. And I

remember telling my dad that, “Dad, some day I am going to pay you back...”

That day when my dad was living in my facility, advanced in Alzheimer’s disease, a light bulb went off. And I whispered into his ear and said “Oh my God, Dad, the day has come. I think I am paying you back.” And he winked at me. This tear rolled down his cheek....

We think of all the negatives of this disease but we had so many beautiful moments and our relationship was so much richer as a result. So my five siblings and I may not have ever hugged and kissed on Dad as much as we did if he would not have had this disease. He wasn’t that kind of man... We were very expressive and sentimental - very. It just brought us together so close and tight.

To elaborate further on what each person contributed to this group, I will share a few more of their narratives about dementia here. The next one is from Jeanene:

I had one lady in a nursing home that had regressed in her dementia to a point where she was in her thirties. (In her mind) she was a new mom and she had a baby; and she didn’t recognize her daughter or her grandchildren at that point. She had a little teddy bear that she had given to her daughter when she was a child. Well her daughter had brought that teddy bear in and could not give it to her because it was too emotionally upsetting for her.

So I went in and talked to her and I said, “Look what I got from your daughter.” I gave her the bear and she recognized it and she could not quite

place it. From that point forward when anybody was entering her room, whether it was to change her or tuck her in, give her medicine or help her eat, you had to do it to the bear first and then she would let you do it to her.

To her, the bear represented her daughter, and she wasn't letting anybody take care of her until they took care of her daughter...That's how she viewed her world, and so in order for us to do for her we had to enter that world. I don't know how many nights I went in there and I would tuck the bear in next to her in the bed. Of course after she was sleeping we went in and took the bear and would wash and dry it and tuck it back in her bed before she woke up the next morning. We did that for three years for her....

I think it is important for people to think that they are part of the world that they live in even if it is not the way we expect them to. It doesn't mean it is wrong, it just means it is different...They need our help to be a part of this world and feel connected to it.

Angela described some of the circumstances in her life that had given her an affinity for elders with dementia:

I left Scotland at twenty years of age knowing nothing and no one. That's what led me on this journey.... Having emigrated from a country to another country that was not my culture - the differences are vast. I can bring a lot of that to the work I do with some of my dementia folks. They're in a strange place and certainly nothing makes sense to them. You look fine, but how come all of a sudden you can't order from the menu, and all of a

sudden you can't remember what you ordered? I really feel for them - I feel that social awkwardness. I can relate to it.

...Everybody brings something. Everybody brings something. I just feel so drawn to these folks.

Elders seemed to be drawn to her as well. Angela went on to describe an incident at a gas station where an elderly lady had asked for her help:

My husband said, "What is it? Even in the gas station! People find you." I hope I give off that vibe. That I am trustworthy. That you give your credit card to a complete stranger. And how honored am I that it was me!

She has gone on to become a senior administrator in Connecticut. She talked about her work there in a way that made it clear she saw the gifts between herself and the elders as going in both directions:

I've been in these people's lives and their families for twenty-one years. I'm a guest in their home. I'm a guest in their life.... They've been through wars and Depressions and loss of families... and eventually loss of self. How can they not be absolute fountains of the wealth of knowledge? When they share with us and they let us in, to me that is such a blessing... They help so much. But you've got to take the time to get there.

Debbie had worked in dementia care for over thirty years before coming to the Memory Bridge training in 2016. When she began, she said, there was little understanding of the condition, which was simply considered "problem people with problem behavior." But in her very first job as a Registered Nurse she discovered what the possibilities were.

She was introduced to an elder who was described as “ a confused, total care individual” and who was no longer speaking. “There’s very little in there,” a member of the staff said. But Debbie began with touch and massaged lotion into her skin and began singing, “You are my Sunshine” to her. There was an immediate response, and Debbie said, “It was like somebody flipped a switch.” She tapped the rhythm of the song on the lady’s arm, then held her hands and put her face close. The elder started to sing as well.

Over the ensuing years she noticed that when someone took time and effort and made a connection like this one, there were “moments of connection and relationship”. She continued to keep a focus on purpose and value of the people who seemed to be locked inside their dementia, and has taken a very person-centered approach to training her staff. She works with role-plays, for example, where her trainees are given life histories and step into the role of residents. She has her trainees think about questions to ask the elders, based on this knowledge. She teaches them that the goal is connection and relationship.

As a further illustration of the attitudes that people brought with them to the training, I will share a “before” story from Ryan, who is Director of a Wellness Center. He remembered working with elders on a storytelling activity called Timeslips:

I recall the moment - it was just this magical moment - that I realized, looking across the room at somebody, “That could be my mother.” In Buddhism it is a teaching, it is a slogan to treat everyone as if they are your mother, and yeah, there she was, metaphorically... At that moment there was a transformation inside of me, and I have never been afraid since.

...The fear was that I was going to do something wrong. The fear that I might get yelled at or get hit or I might just freeze and not know what to do. That I might hurt somebody or whatever. I might sit down in a chair that had been urinated in. Anything, really that was just out of the ordinary. Because when you are in the land of memory care, you are not in an ordinary land. And I realized in that moment that none of that matters; none of that matters if the person that I am with is my mother or my father.... So it just sort of erased those fears of having to do everything right. It created the opportunity to do things authentically.

The trainees not only brought with them some extraordinary experiences, and an attitude of respect towards elders and others with dementia, but seemed unusually insightful as well. Jill described her group in 2015 as “some of the most emotionally intelligent people in the world.” Both Michael and Jane used the word “special” to describe them. Susan said,

I thought—and I know a number of my colleagues thought—that however Michael and Jane managed to put the group together, whatever magic they used to decide how to constitute the group, it really did seem to a number of us like magic. I've done a number of things where the make up of the group is pretty essential. I've never experienced such an incredible, wonderful, mutually supportive, coherent, mutually beneficial group of people.

I shared these positive impressions of both groups, and I asked the organizers how they perceived Memory Bridge as adding value, given that the people who came already

appreciated and respected people with dementia. (This is a point I will return to at more length in Chapter 4.) In response, Jane noted that the care partners' perspectives were often undervalued in their places of work. The training,

Gives them the tools to explain what they're doing, or model the behavior...

They might come knowing that those things are important but they might not know how to talk about that, how to advocate.”

She also considered it an important part of the pedagogy that each person brought his or her unique experiences and wisdom to the retreat. It enabled everybody, including herself to learn more. This point reflects Memory Bridge's emphasis on community as a relationship among equals. Real learning and help are reciprocal. It explains Michael's ambivalence, too, about the word “training.” Jane said of the trainees,

They are very articulate people, much more than myself.... I learn a lot from them because of the depth of their experience, and their willingness to be emotionally present, and to share their feelings about what's going on, and to open themselves up to what's happening and to each other, and to be vulnerable.

Michael observed that the people who were drawn to Memory Bridge had often been experiencing something missing, even when they worked in progressive and innovative care environments. He outlined two processes that, he hoped, benefited the people who attended. The first echoed Jane's point about participants gaining tools for public advocacy:

There's something about this experience that crystallizes a vision for them.

In other words, they may have already been resonating with basic commitments – say non-judgmental, that kind of thing – but (they gained) the idea that there was a kind of dis-ease that could be healed by a certain quality of attention; and that this constituted a front on which we could mount up an intentional outreach.

His second thought was that the trainings gave them rare emotional experiences, especially their time with “buddies” with dementia - which was part of the daily schedule - and their bonding with each other. He intended for these enriching experiences to be resources they could draw on when they returned to their work in caregiving.

There was an interesting echo for me as I read back through the transcripts where Michael and Jane talked about the process of gathering participants. In their interviews and applications many of the applicants reflected on how much they had learned from elders with a dementia diagnosis, (and in fact the respect they displayed was one of the criteria for selecting them.) The organizers, in turn, reflected on how much they learned from the participants who came to attend the trainings.

CHAPTER 3: THE ELEMENTS OF THE CURRICULUM

I will take the components of the training chronologically, thus introducing the reader to each activity or feature in the order that these were introduced to trainees. This will give a sense of the trajectory of the two retreats. Most of the activities recurred regularly during the five days, and in the cases where I have enough information from interviews I will also try to describe how people's perceptions of them changed or progressed over time. The curriculum was designed with the idea that its different activities would complement and build on one another. The elements overlapped, but each contributed something important of its own. The first element of all was Memory Bridge's provision of food, shelter and a quiet space, so I will begin there.

The Material Aspects of "Feeding the Feeders"

There was no charge at all for the Memory Bridge participants' room and board or any other aspect of the program. Jane observed that "feeding the feeders" is more than a metaphorical phrase. "They get fed literally," she said. "They feel like they've been taken care of." Practical assistance began before the retreat itself. Jane made sure that everybody got travel directions and guidance about what to bring. If someone was flying in, she arranged for them to be picked up at the airport. They drove, or were driven, to the eastern edge of Bloomington in Southern Indiana.

Their destination – the retreat site – was the Tibetan-Mongolian Buddhist Cultural Center.²⁶ It is set well back from the road, and is surrounded by a wooded and secluded piece of land comprising a hundred and eight acres. The retreats were held in early June; a time of year when leaves are out, flowers are in bloom and the temperature is (usually) warm rather than hot. Around the well-kept grounds there are hiking trails, which follow along a creek and circle a substantial pond. The trees are mostly deciduous – a mix of tulip poplars, oak, elm, hickory, walnut, aspen, maple and beech, and there are beds at the various entrances where day lilies and other flowers grow. Here and there are artifacts related to Tibetan and Mongolian Buddhist traditions, including two gold and white stupas, flags of many colors, a prayer wheel and a sand mandala. One of the two largest buildings has an elaborately decorated meditation room, with murals and statues of Buddhas and bodhisattvas. There are also meeting areas, a kitchen and a dining room. The staff at the Center provided three meals a day during the retreat, with vegetable and meat options and plenty of choices. Pairs of participants shared either a room in one of the center’s two main buildings or in a yurt nearby.

In many of the “after interviews, the trainees expressed appreciation for the surroundings and meals, and for all the care they received. Carolyn said, “The lily pond, the woods, the Tibetan art, the fireflies, the quiet – all these spoke to my core. I hadn’t realized how much I needed them.” Greg noted the subtle features, saying, “I think there was love in the setting, in the presence of the monks, in the respect and kindness and gentility.” Molly appreciated the contrast from her city environment:

²⁶ The Center was first established in 1979 by Thubten Jigme Norbu, who was the Dalai Lama’s elder brother.

I live in New York City, so the space was much different for me. You don't have a lot of alone or quiet time. If you think about the city, it is really bustly and very loud and even if you are alone in your apartment you are around a lot of people.

Several of them noted how rare and good it felt to have time for themselves, and time to reflect on their work and lives. Carolyn said,

The 2015 Memory Bridge retreat came at a time in my life when I was intensely focused on helping other people -- my mom with dementia, and my teenage daughter preparing to leave for college -- and I was exhausted by it. The retreat itself was a blessed opportunity to get away from both of those responsibilities and spend time reflecting and learning.

Julia also expressed how valuable it was to her to have time away from responsibilities:

“There was space, there were five days where I didn't have to go to work and didn't have to make dinner; and the actual place, and the land.” And Cheryl noted that the training retreat gave her a chance to process her mother's recent death. She said, “I don't think I've allowed myself that time to grieve for my mother or to reflect on the deep things. And all that came to the surface in that week.”

Michael considered it important that the training program was free, and that it was not in any way a money-making venture. He remains concerned about the disfiguring effect of money on dementia care (as well as many other aspects of society) and he wants to keep Memory Bridge free of this:

There's nothing about it for sale.... You feed the feeders. They're emotionally feeding people with dementia. Then there has to be a community in which the feeders are being fed. So I'm just trying to demonstrate that it's possible.

Marigrace summed up a widespread appreciation among the trainees of Memory Bridge's disinterest in commercial gain:

It feels like there is an openness to Memory Bridge and not a grabbing, of "Okay, we need all of this to happen", or "You are not going to get anything from us unless you pay for it."

Michael also wants to avoid treating Memory Bridge as a "brand." After the training, he stressed that, for those who attended, "There needn't be any, even indirect, connection to Memory Bridge as a label." Mary Jo expressed her wish that expectations of how to apply Memory Bridge's principles after the program could be made explicit in future years. But for most people the lack of pressure to refer to Memory Bridge by name or to report back on how they had applied what they learned was a very positive feature of the training.

Brenda, for example, noted the relief she felt at discovering this aspect of Michael's approach:

It was our first night and our first circle and Michael said something along the lines of "you are under no obligation to do anything with this." And I cannot tell you how freeing that is. But also I think that it creates a real space where someone can much more embrace it. That nobody was feeling like, "Now here is the sales pitch coming and Michael is going to ask us to

do A, B and C.” So that was a beautiful dichotomy of you don’t have to do anything and now suddenly we all *want* to do something.

Pat expressed a similar feeling of relief:

This is about him sharing the beauty of what he's come to understand when walking with someone who's journeying through Alzheimer's, as far as ways to connect with them outside of what people traditionally focus on - which is spoken, thinking type of communication. And that it was for us to experience at first hand with our buddy. Not be sitting there the whole week worried about “Okay. I go back home and set up a group and do this and do that and other and...” He relieved that, (big sigh) so that we could actually just be IN the process, and that was one of the most profound things; because it's rare that someone who's living their mission and vision gives you that type of gift.

And we've all been raised and informed and cultured to always be going for this certain, tangible, analytical outcome. Where they've documented and taken notes, and what you've got to take back is some type of stamp, proof of why they were there. He really just allowed us to be present. In the present of his vision. And that was a beautiful thing.

Sarah too acknowledged the lack of pressure to produce an outcome, and commented on how unusual it was for her to receive gifts for herself, as a caregiver:

I found it just remarkable that all I have to do is get myself there, and there is this wonderful space where I get to stay for free, and wonderful meals and

wonderful exposure to this wonderful Buddhist culture and this sharing. I just felt like it was such a rich environment; and to be given that and no expectation of a return.

When Michael says “You don’t have to do a dang thing with all of this stuff,” to me that is very rare in this world and you know it is for real. You can really feel it. It just doesn’t happen very often and so it is a deep sense of being included and appreciated just for being there.

The thought of the words that I said before, of no expectation of return, brings tears to my eyes. You know caregiving... it is incredibly exhausting. There is a lot about it that can be rewarding, but you are always putting yourself second.

Circles

After arriving, establishing their sleeping quarters and eating the supper provided by the TMBCC staff, trainees came together for the first evening in an opening circle. Group gatherings like this were repeated regularly throughout the retreat. People talked about experiences with the elders they meet at the nearby Memory Care center, they discussed shared readings and they exchanged advice and stories from their lives. At the first circle in 2015, Michael asked each person to talk for about three minutes about his or her connections to dementia. Many group sessions were structured, so that people took turns talking. A few were “popcorn style” with no predetermined format.

According to most of the trainees, the circles enabled mutual learning and there was a back-and-forth relationship between the group meetings and the time in the memory care unit, as people could come back and share their experiences with elders and talk about ways they tried to communicate or listen. Participants built on each other's insights, worked with these in some cases in their visits to the memory care unit and came to new understandings about their own lives. As Greg said, "We learned a lot from each other and from the experiences that we had; and then from reflecting on the experiences." Emma expressed this idea as well:

What makes the whole retreat so special is their focus on the experiential and the sharing of what that's like; and reflecting back on what happened and the responses. Each time I would pick up new things to explore and new insights into people's experiences that I can apply back to my own.

Among these varied groups of people, an overwhelming majority had good things to say in their interviews about the time in the circles. This included introverts as well as extroverts. I will bring up my own experiences here because I am typically more comfortable talking one-on-one than in a group, so I can report on my visceral reaction to the discussions through an introvert's perspective. At the very first circle in 2015 I remember feeling fear as my turn approached, followed by relief and an enhanced ability to listen once my turn was over. I also felt welcomed and kindly received by the group to an unusual degree. After the opening in 2015 I wrote in my field notes that I went home with "a belly full of joy" after the first night's circle. In 2016 I wrote that I felt a sense of relief in the opening circle, as if "sinking into place."

Susan, like me, considers herself an introvert, and she also became comfortable very early on in the retreat:

I came in with a desire to be open to everybody, but I'm also a relatively shy person —so, I think there's a little protective gear that I wear sometimes. But I've got to say, after being hugged by three people I didn't know, all of whom were younger than me, and all of whom were—I kept meeting each one thinking, “I thought the *other* one was the sweetest person on earth; clearly *this* is the sweetest person on earth.”

I think the tremendous age span in the group was just wonderful. And I guess that in itself wouldn't necessarily have led to the terrific bonds that we all forged. Because I can imagine a situation in which the older members of the group would just hang out by themselves and the younger members would hang out by themselves. And clearly, that did not happen here. But it was certainly one of the things that I loved about this group. I loved seeing Donna mentoring Maggie and Maggie teaching Greg how to sing.

Since there were circles throughout the five days, people's perceptions of them went through changes. Sharing touched on vulnerable issues and occasionally brought out insecurities. Much of the literature on therapeutic groups and conflict resolution²⁷ notes that the sign of an effective group is not that its interactions go smoothly all the time, but that conflicts can be aired and resolved without leaving permanent rifts, and without silencing particular people, particular types of experience or particular sub-groups.

²⁷ See Isenhardt and Spangle, 2000, Jones and Brinkert, 2008

In 2015 there was a marked contrast at the beginning between the most introverted group members and the most expressive. This led to a few of the quieter people feeling that the more talkative ones were cutting too much into the time designated for the rest of the group. Meanwhile a few of the more extroverted ones felt that they were being rushed. This tension was resolved in several ways; and these ways provide good demonstrations of how potential conflicts were typically addressed at the Memory Bridge gatherings, and how community was built at the training retreats.

One process that helped was that a small group of trainees - which included both expressive and quiet people - talked informally about their frustrations together outside of the circle. A participant told me how this worked:

We talked through the whole thing and got to the core of it and how it affected us.... We talked about the cell phone timer and if the time limit is set for five minutes, we will make that three ... and the people who are real time conscious it will give an end, and the people who are not time conscious then it will be okay to run just a little bit over.

The topic was then brought up again with the whole group in the next circle, and they adopted the timer plan. This second discussion also proved productive:

It could have turned into a big fight but it didn't... Every single person who (had been) talking (about it) contributed; and talking it through and processing through and working through it with each other in a very gentle and positive and amazing way to come up with a concrete solution.... I am so glad that we had this conflict because, again, authenticity led to deeper connection.

Another factor in resolving this and other potentially sticky challenges was the explicit ethic of transparency and mutual acceptance that was established at the training, reinforced both through Michael's talks about interacting with people with dementia (which will be discussed below) and by group practice. If acceptance was an ethical goal where elders and those with cognitive differences are concerned it was reassuring to see that it was also an ethical goal in relation to the people in the groups. The unconditional nature of these goals was put to the test when a conflict, difference or problem arose. In the example above, differences in styles of expression seemed to be handled well. In 2016 several trainees had concerns about the way the group entered the memory care unit, Autumn Hills, and made their first approaches to the elders they were to befriend. They expressed this in the circle, and their suggestions were taken up by the whole group, with Michael's support.

Gina also appreciated the various attempts to structure each person's time more effectively, and said,

I loved the circle, always loved the circle....It centered around personal growth and sharing and was very emotive. I found myself really connected to people's personal journeys and stories, and full of emotion every day. I am in tune with people that way with my innate empathy. I also found the I-land map very insightful.

Throughout each training retreat this ethic of acceptance pervaded the meetings; there was a sense that people were willing to receive one another in all their humanness and differences of opinion. The trainees express this more vividly than I can, so I will share a few more of the many comments, and of my own impressions of the circles.

Cheryl is a trainer in health care, specializing in disabilities. She has worked on interacting with people who cannot use words, and she also has memories of trying unsuccessfully to communicate when she was a child with epilepsy. Because of these experiences she is especially sensitive to the importance of communication. In the circles, she said, she found herself telling people things she had never told anyone, because of the level of attention the group were giving to one another:

Until you're actually in it, you forget how powerful it is to have yourself acknowledged as somebody with something to say. And to know that people are listening to you is an incredible thing.

One of her examples illustrates how this attentiveness extended not only towards her words but towards her non-verbal cues:

Somebody was telling a story. And my eyes kind of welled up; I had tears, I was emotionally affected by the story we were hearing. And Maggie just reached out. She knew that I was upset, you know. And she just reached out her hand, and she just touched my arm, and it was like a lightning bolt. It was just what I needed.

She also explained how these experiences translated directly into her interactions with her buddy at Autumn Hills:

People with dementia don't express their needs to you as much. Because their speech isn't as readily available, they don't voice to others what their needs are. And I guess that's where we're learning in our circle: to read each other's body language better... (Maggie) just picked up. From my body clues

and my body language. And I know when I was working with Matt, I didn't want to just go in there and hold his hand; I didn't want to just touch him for the hell of it. So I was waiting for those cues and those moments when I knew that that's what he needed.

In 2015, Angela noted how marked and unusual the ease in these gatherings was for her: “We came to the circle and we could exhale. We got intimate very quickly. I’ve been to other retreats and there was not that sense of true connection.” Emily also noticed an unusual and rapid development of intimacy in 2016. She said, “I’ve never quite felt that type of closeness and trust emerge across a group in such a short space of time.” One of the rationales for the circles, and a core principle of Memory Bridge, is to create a feeling of community that can then be passed on to elders. Based on the interview responses this worked, and participants developed strong emotional connections. Heather appreciated the support that came from the circles, noting, “There was always someone there to hold you up.” The sense of community that developed inside and outside them was a very important part of the training for her. She said, “It was just hilarious to be so in love with a group of people.”

Julia typically finds talking in a group uncomfortable, and has a tendency to doubt whether people will be interested in what she says. But this changed over time at the Memory Bridge training:

I felt an accountability around showing up for others, and I wanted to be authentic and show up in an authentic way. And I also knew that I wanted to share and that others would be sharing in a vulnerable way, and I think it is respectful, it honors the process for showing up and for each other.

Each time somebody was received with interest and without judgment, his or her sense of safety increased. Marigrace expresses this well. She appreciated,

The pleasure of feeling like all of who we were, as participants or members, was welcome and could be brought to bear on our discussions and our experiences and everything else. It felt super freeing to me to be in an environment where I did not have to hold back some part of myself.

It was crucially important, also, that Michael demonstrated acceptance and non-judgment in practice with the people in the group, as well as advocating these qualities in relationships with elders. I noticed that he received each speaker positively and often referred back to images or incidents that people had brought up earlier - showing his own attentiveness. Thus themes came up organically and people's contributions were acknowledged, were developed in the group discussions, and were incorporated into his talks. As I noted, on the few occasions when there was a problem to resolve he was flexible in his role as facilitator and willing to listen to the group. In 2015 he took up the timer suggestion mentioned above. In 2016 he made changes in the way the group approached the elders at Autumn Hills - also on the basis of group feedback.

Magdalena noted that the circles, and her ability to listen within the circles, evolved over time. She said that the training process and the accumulation of shared experiences made the final gathering especially meaningful for her:

What I really liked about the last circle was that I had personally arrived at listening to every single person deeply before it came to me to speak, and I think I was - I can't remember - second to the last or last. It didn't matter any more where you were. But while maybe sometimes before you would

get side-tracked or you would at times think about what you were going to say yourself when it was your turn... I felt that everybody had something really profound to say, and said it without self-importance; and therefore it was very easy to listen and to listen fully.

I will conclude this section with two quotes that suggest effects from the circles that went beyond the circles themselves. Susan noted the way they helped her to reflect on herself:

I remember hearing that you are going to really find yourself thinking in very profound ways about *you*. And I thought, “Well, that's kind of funny. I mean I thought I was here to think about other people.” But then, I saw exactly the point, once we started with the circles.

And Emily commented on the effects of the time in circles on her later work with dementia care:

When you've been on the receiving end of such emotional generosity, you can't help but be caught up in wanting to pay that forward - and also understanding how that feels, and then bringing that into your interactions with people with dementia as well.

Meditation

Early each morning the trainees gathered for a meditation, led by Geshe Kunga, a monk who is the spiritual teacher at the Center. He gave a short talk before each meditation, which was translated by another monk - Tenpa Phuntsok. The topics in 2015 and 2016 included an introduction to Buddhism, craving as a cause of suffering, the

importance of compassion and the elusive nature of the self. These were themes that tied in with the central aims of the Memory Bridge training, and which Michael sometimes referred back to in his own presentations. The talks were followed by traditional chants from the Buddhist Sutras and then ten minutes of silent meditation.

Almost all the participants I interviewed expressed appreciation for the morning meditation sessions. For Magdalena, Greg and others they were a highlight. Heather said that the meditations helped her to “take in pain and let it go.” Donna noticed that the meditations supported the theme of listening in the training as a whole; “That was me, listening to me,” she said. And Ryan pointed out the connections between meditation and the capacity to be present with people with dementia (and with other people as well):

I think it takes awareness - but also commitment, once you become aware of it, to constantly work on dropping the expectations. Because being aware isn't enough... if I don't change my behavior towards that thing then *all* I am is aware... There needs to be a commitment to letting go, moment by moment. And that is where I think the practice of meditation is so helpful.

Similarly, Christiane noted the way meditation reinforced Memory Bridge's philosophy of compassion and inclusion:

Very vivid for me was the meditation! ... This is necessary to know how to strengthen this attitude of compassion... for me, this is really, really essential. And I think it's so clever to organize that at this place, where it is just normal, where these are just normal things, and we can dive into them and be there, and share them.

Two people said in interviews that they experienced some inner conflict with their own religious faith, because the meditations were introduced as part of a Buddhist practice. A third, Stuart, considered that the training was too focused on Buddhism, given that the same principles could have been learned from most faiths. Only these three participants expressed qualms about meditation in interviews however. Mary Jo suggested that the morning sessions be optional, to allow for people of varied religious backgrounds. For another, meditating in front of statues and images in the meditation room sparked a crisis of conscience. This person overcame the inner conflict through the realization that it was not a serious threat to Christian faith, was less of a threat, in fact, than other common kinds of “bowing down:”

I am not going to go and get myself a physical golden statue and want to bow down to it. But there are plenty of things in my ordinary life where rather than concerning myself with what God has called me to, and what pleases him, I'm thinking “Oh my gosh! What is my supervisor going to think about this?”

It was helpful to this person to feel able to speak about faith, to at least touch on these tensions during a group meeting, and to be positively received.

But as noted above, by far the majority of the people I interviewed said that they valued the meditations. They appreciated the chance to learn from Geshe Kunga. Here, for example, Donna, describes the way the meditation and the talks wove in with, and complemented, the retreat activities:

I think that it really was everything interwoven, beginning with our circles the first night. But also very much the practice of meditating, and

particularly once we had the Buddhist monks leading us. It gave me a sense of quiet that I had been searching for in my meditation. And it was wonderful.

The Buddy Visits

On the first full day of each retreat, participants came together in a circle to read through folders with details about the history and interests of residents of the nearby memory care center, Autumn Hills. Christiane noted the respectful way in which Michael presented the elders' biographies:

He walked out and he got some cushions... something to put them on a little pedestal, a little higher up. Looking at the bios is a very precious, precious thing. I mean it was only a piece of paper, but it had a lot in it, and it had a lot of meaning, insight. The way he made it into a precious moment, put them there, put them, and let people select them - not having any pre-set ideas of who should have who... this I really liked a lot.

Each trainee picked a single folder with the aim of finding out about a particular elder, and ultimately developing a relationship with him or her. After these introductions to their chosen "buddies" on paper, the whole group went to Autumn Hills, where the participants sought them out in person. They spent about an hour on each visit. These interactions were repeated every day and were central to the trainings. The buddy visits were where people had direct experiences of being with elders. Michael stressed their importance as the main source of learning over the five-days.

Because of this emphasis, I saw Memory Bridge trainings as one of the very rare environments in the world where people became anxious about not “measuring up” to the cognitively frail – one of the very few social environments where the arbiters or “they” who Michael talked about in Chapter 2 were people with dementia. In both 2015 and 2016 I noticed a certain emotional intensity at the circles following the first of the buddy visits. My impression at this early stage of both of the trainings was that, to varying degrees, people wanted to be acceptable to the group, which was still new, they wanted to show that they were worthy of Michael’s good opinion and they wanted to show their capacity for “being with” the elders. They also cared a great deal about working with people with dementia, and wanted to do the best they could.

Not everyone showed or talked about this kind of initial anxiety. A substantial number of the participants were very experienced in everyday interactions with cognitively frail elders. As noted earlier, some held senior positions in elder care, like Debbie, Mary Jo, Natalie, Jeanene and Angela. Others, like Maeve, Susan, Pat, Stuart, Greg, Carolyn, Jill and Sarah, had long histories of living with or working with elders and they too approached Autumn Hills with an ease that came from experience. Jill noted how natural the buddy visits felt to her:

Getting with my buddy and communicating with my buddy, was very easy for me... I didn’t do anything different. Sometimes I was like, “Is this a movie, did somebody script this? Is this an actor?” And Michael, said “Jill, I would like to propose that maybe there is something about the way you are, that made this man feel like you were really interested. So that he felt like it

was worthwhile to talk about substantial things with you and not just about the weather.”

And I go back and I look at my work and interactions with people and realize that my whole life, people tell me things - people at the waffle house or in school... There is something about the way I am that makes people feel safe and lets them know that I am authentic and interested. I am already doing this and okay, this is cool, this is good. And so that was big. And the other thing that it made me realize is there are a lot of people who *don't* think like that and struggle to do that. It is not obvious to many, many, people; and that is where the education piece comes in.

There were some participants who had had fewer direct interactions, so that this was a relatively new experience for them. There were also, inevitably, different personalities and life circumstances among the elders, and they had different feelings towards visitors on different days. All these factors made for quite a variation in the interactions between Memory Bridge participants and their buddies.

When early visits went badly for trainees, this presented emotional challenges for some of them, not only because they had to process the difficulties of the interaction itself but because at this stage of the retreat they risked disapproval (or at least imagined that they did) from the elders, from the group - which was still relatively unfamiliar - and from Michael. Ryan expressed this clearly:

There was another expectation; like Michael is going to be watching us and this is kind of a homework assignment. We are all high achievers and we wanted to do well and not be, to use Michael's term, “dis-membered” by

being seen as failing at this. So I think everybody felt that way... In this case it is an expectation on ourselves and also in some ways also Memory Bridge. But I think over time it faded; I think it faded very quickly actually.

In both training sessions, a handful of the meetings, especially in the first days, were difficult and emotionally fraught. Heather's first meeting, for example, was with a lady who seemed angry, afraid and disheveled:

Each time we would go and visit our friends at Autumn Falls, I would interrogate myself on this mammoth amount of emotion I was feeling...

I was scared I would upset her. I was scared she'd have an outburst. I was terrified, always, of what was going to happen. And I realized that SHE was scared. What was *I* scared of? ...I didn't need to be scared of her. I was then aware that I was feeling *with* her and that I needed to maintain my course.

And I needed to contain my way of being, so that when she needed reassurance, she had it.

She also noticed that the elder's resistance to receiving love mirrored some aspects of herself; and she took this to heart as a reminder and an important insight:

My experience with my buddy was intense, because she would rigidly fight me. She would rigidly fight my love until she relaxed, and then she would take it. And it was hilarious for me to say (to myself), "Oh my gosh! Did you need a person in your life to show up? To show how important it is to relax and take love in?"

...It really felt like it was a metaphor for - "You cannot be loved until you let love in. And you really can't love fully until you feel that you have been loved."

Heather's experience was partly shaped by painful associations she had from childhood of people who expressed anger. It was partly shaped by her empathy for her buddy - who was suffering. It also increased her empathy for caretakers - people she is in regular contact with through her work:

There's thousands of people in my community who as caregivers are having what I experienced - the fear, the awkwardness, the not-understanding; but wanting so much to help, but not knowing quite how.

Julia also came away with a greater appreciation for, and understanding of, care partners, (whom she often interacts with in her work as a crisis phone counselor.) She developed rapport with several of the elders at Autumn Hills, but the buddy whose folder she had chosen did not seem to want her company:

Every day when I would come, he would tell me to go away. I mean he would entertain me for a couple of minutes and then he would be like "Okay, bye."

I am glad that I had this guy. I am glad that I did not have this sweetie pie, because it was really helpful to be reminded. I have worked with people with dementia before, but sometimes it is tricky which way to go, and it is not clear. And it is not just as simple as sitting with someone and being available and being present with them. Sometimes that is just not possible.

So, yeah, that is nice for me to continue to have that empathy with caregivers because I had that tricky situation.

Emma, like many others, experienced a shift – going from a feeling of awkwardness as she worried about intruding on her buddy’s space to “breathing past that” and initiating contact through song and touch. She drew on her memories of the discussions people had been having in the circles about what Michael calls “The Valley of Awkward.” Here she made a connection between themes in the circle, time at Autumn Hills and interactions in her daily life after the retreat:

That's a nice life-long lesson for me that I've been bumping up against for a while - it came through very strongly for me. Particularly in this work, recognizing how important it is to be willing to step into that space where I could easily get really uncomfortable and really outside of my line of normality. And just really experiencing for myself what that felt like in terms of the space that it opened up with Joanna when I was willing to be there. And I saw it in everybody else's experience - really strongly- as well.

And it continued to arise for me, during my time and my interactions with anyone in any walk of life.

Ryan, Magdalena, Julia and Angela worried that they had tried too hard to connect on their first visits, with elders who did not necessarily *want* to connect with them. Angela said,

My buddy was a man of few words. I don't think it's that he didn't have words. I think that's who he was. I draw that parallel, as a child, of feeling uncomfortable and not knowing what to say or if I should or if I shouldn't...

She wondered

“Is he uncomfortable or am I making him uncomfortable?”... He didn't necessarily want to make deep, or any, social connections. We can't expect that from all people. They have a different emotional history that we don't know. We so much wanted (connection) but it was all based on the assumption that our buddies wanted that too. That for me was the “Valley of Awkward.”

Similarly, Ryan learned to be willing to step back from someone who wanted space.

He ended up having loving interactions with his buddy by the end of the training retreat:

I had all the best of intentions but she was afraid of me. And my insisting that she let me into her world for an hour was aggressive, even though I meant to do it with love and just to support and warmly embrace her energetically... The appropriate thing to do, the loving thing to do, was to honor her and her experience and her emotions and not press myself on her like that. So that was a really keen learning moment for me.

The second time he visited Autumn Hills, he approached her quite differently:

...The next time that I saw her, I encountered her in the hallway, walking. I said “Hello”, she said “Hello,” and I asked how she was doing and she said “Fine,” and I said, “Oh, you are going for a walk?” and she said, “Yes I

am". And I said, "May I walk with you?" and she said, "No", and I said "Okay, well have a lovely day." And I left and went and visited with someone else.

But the quality of that relationship, that interaction, was so different. I acknowledged her and she acknowledged me, and then I acknowledged that she did not want me there. And maybe on a subconscious level she felt affirmed of her own personhood....Loving is learning how to let go of expectations, including the expectation that being with someone means physically being with them

Here his description of their final encounter:

I did have this experience on the last day with Linda. She is not very verbal because I think that she cannot converse very clearly, but she kept saying, "Oh, I love you", and I would say, "I love you too". And at one point I said to her, "What does love feel like?" And she just looked at me with those crystal blue eyes and said, "Well you should know." And for some strange reason I had this really strong emotional response to that, and my eyes just filled with tears and I said, "Oh you are absolutely right", and I laughed.

...That is meaningful, that someone with dementia, a stranger with dementia, could touch me... I didn't realize that that could happen....But it is just really the magic of human interaction - that is really all that is.. It could be any human. It could be someone who is fully aware and mentally awake, or it could be someone that is in the last stages of dementia who says exactly the same thing and has the exact same effect on me. Who knows?...

What I come down to - the basic common denominator - is that we are humans with two souls that are connecting.

In 2016 a few people expressed uneasiness about their initial arrival at Autumn Hills because they were uncertain about how to explain their presence to the elders they met. Several participants suggested an explicit rationale for the visits, where the elders' roles as mentors were emphasized more explicitly, rather than them being positioned as people at risk of isolation and in need of help. Stuart suggested not going in with biographical information, in case it felt intrusive that the trainees had access to their personal information:

I'd like to see people go in with only a name. No age, no history, and nothing about their family, and just see what they can gain by saying, "Hi. I'm Stuart from Australia. And I believe you're Mrs. Keller," and then, "I want to spend some time over the next few days. Would that be all right? Can we have a chat? What would you like to chat about?"

In the circles following the first visit that year the trainees came up with ways to smooth out the group's entry into the institution. They suggested having staff members introduce them individually to the elders, and also suggested staggering their arrival at the building by having just a few people cross the threshold at a time, rather than all at once. Michael took up the suggestions and arranged for introductions. As with the issue of talking time in 2015, this was a crucial turning point, at which there was potential for conflict in the group, but where it was resolved through communication. Michael's willingness to listen and make changes on the basis of trainees' suggestions was appreciated by Susan, Magdalena and others.

Cheryl noticed a contrast between the first visit and the second. Already on their second trip to Autumn Hills, she said, the trainees had lost most of their self-consciousness:

The first day of the buddy visits was very nerve-wracking. I think we all were kind of on edge, and we didn't quite know what we were there for, what we were going to have, we were all full of anticipation. The second visit, nothing mattered, we all relaxed very much more.

While, predictably, not all the interactions went smoothly, most people had something positive to say about learning from the buddy visits by the end, whether these were challenging or easy. Greg has had a lot of experience with dementia care, since his wife, who lives with him, has this diagnosis. With her he is respectful and attentive, and they have maintained a good relationship. Yet he felt that he never really broke through with his buddy at Autumn Hills, partly because of their different personalities and values:

She was a real estate salesman, in her former life, and I don't think I got below that person who was out there kicking butt and making sales. On the other hand my disappointment in that area was also a memorable experience. It was a humbling experience. Those are sometimes the best.

He noticed that as the training progressed he became “more attentive to being attentive” with his buddy and with the other trainees as well.

Susan had a good connection with her buddy, which confirmed some of her previous ideas. She had come in to the training questioning mainstream assumptions about

dementia; in particular the widely held images of a one-way flow of help from kindly care partners to helpless elders:

Lottie, every day, seemed to really recognize that she had seen me the day before, and she was very friendly and we had a wonderful time together. But what I learned—and maybe, you know, maybe in the end, my idea that I was going to be mentored by somebody with dementia—maybe it was true. Maybe I was mentored, and what I was mentored to learn was this is a self-assured, independent-minded, very centered person, and what she's teaching me is, “Don't think that just because I have dementia, I need you or anyone else to come on a mission of mercy.”

Magdalena's relationship started badly but went on to be valuable for her. She said that her time with her buddy was her most significant learning from the training. At the time of the 2016 retreat, Magdalena was the Artistic Director of “Hearts & Minds” in Scotland. In this role she had created the Elderflowers program for people living with dementia. The Elderflowers used physical theatre, clowning and red noses to connect with elders. Her visit to Autumn Hills put her in a different role and context. On the first day her buddy did not want to connect with her and seemed suspicious about why she was there at all. Magdalena was concerned that she had caused distress. She also felt unsafe on that visit; there was a stretch of time when she was unable to leave her buddy's room. As with Julia and Heather, this experience increased her insight into challenges for care partners:

What I took away is the helplessness that maybe a relative would feel or staff may feel. I didn't have the connection with the person I was with; she

was not my mother. I didn't have that sort of history to relate back with. But I would say that the empathy of trying to make a connection to somebody who doesn't necessarily want to connect with you - I think that was, for me, the biggest learning.

To be rejected by a person - that was to me something new, because, to be honest, that has never happened to me in that environment. That was very interesting. And I think this is... very often what happens to relatives and staff. To relatives when they are no longer recognized by their own relative with dementia.

Magdalena added that before the training she would not have gone back. But she did go back. She made changes in three ways, first by,

Creating a story that was true but could be presented in a way that was easy to understand, with simple language. I changed my seating position to shift the feeling of power... And I changed the circumstances, like kept the door open.

In the following days the interactions improved markedly. She established a good and mutually respectful relationship with her buddy and they maintained contact until the latter's recent death.

There were changes over time in Stuart's visits with his buddy also. He described the way his relationship with Janet developed:

The first day, Janet was very suspicious. It was almost like, "I've had people visit before and they never come back." The next day there was

recollection, you know, but sort of still standoffish, “You're pleasant to talk to, and I'll talk to you, and yeah, you make me laugh every now and again. So, I'll put up with you.”

The third day she went to the doctor, so I met Joan, and Joan was just staring at the table. And it took some time, but eventually her head rolled up. And she looked into my eyes and I felt that instant connection and the smile came to her face like, “You're speaking to me and you really are taking the time!” That's what she was telling me with her smile and her eyes. “He's just going to sit with me. Isn't rushing off, isn't just saying a few kind words and then disappearing. You're actually sitting with me.” So, I got something from her.

And then on the fourth day Janet came back, and she was sort of getting ready in her room when I went looking for her. And I was way down the end of a corridor. And she's obviously got really good vision, because as she came out the door or around the corner, as soon as she could see up the hallway, she saw me standing there, and her finger came and pointed and a big cheesy grin came right across her face. She was wagging her finger at me (chuckles). It was like she was directing admission like, “Yes, you're back.” And my heart skipped. It just welled up that I'd been able to introduce that to Janet. To give her something.

Debbie's visits provided her with a powerful demonstration of the importance of drawing an isolated person back into relationship. When they initially met, her buddy was using repetitive motions and making repetitive sounds. He seemed disconnected from

people, as though he had given up on trying to communicate in any meaningful way. She began by approaching him with touch, songs and stories, and by commenting on the photos in his room - images she thought must have had value for him. She said it was helpful to have read through his profile. She learned that he had worked in the railroad system. It was important to him that she acknowledged this part of his life.

After a few visits, astonishingly, he was holding conversations with her where he used whole sentences, told stories, made eye contact and exchanged gestures of physical affection. Her most vivid memory from the retreat is of her last day with him. She told him that she was going away, and she has not forgotten his response. She said how meaningful it was for her,

For Tom to hug me and thank me, and say, “Don’t stay away too long. I always like it when you come.” His response was such a gift, affirming that we made a bridge, we were connected, and walking in relationship in the moment. That’s what this retreat is all about....learning what that looks and feels like.

For many people the interactions with their buddies were highlights of the training. The trainees expressed these relationships in reciprocal terms. Here is Gina, for example, talking about her time at the memory care unit

When I was in Autumn Hills with my buddy Elena, some days I was with her and we spoke for a while, some days I just held her hand. One visit I massaged her feet using my skills as a Reflexologist. She had never had her feet done - the power of touch is amazing - and the way her face lit up when I was with her in that moment highlighted our connection.

In some ways it was just that we were together, the two of us with nobody else around. It was surreal. It was important for me as well. It was two way completely.... There were some moments with my buddy Elena where I felt extremely connected with her It was like we were *one* at certain points.

And here is Marigrace:

I am so grateful for my buddy - her willingness to be with a stranger that is coming in and staring at her, and suddenly being really close to her. She just went with the flow and was accepting, and showed a lot of extraordinary flexibility and openness.

Maeve found it a luxury to be able to sit down with her buddy for a whole hour at a stretch, since this was rarely possible for her at her place of work. Molly also relished the opportunity to spend more time with an elder than she was usually able to:

I work in a nursing home, so I am in that environment all the time. But I never really get to take the time to just be with people, and that was really valuable.

Christiane expressed a lot of appreciation for the lady she met:

I was so lucky with my buddy - this was so nice. Such a wonderful, wonderful person. To be able to make the whole journey here, to be able to meet this person, because she was so nice and so sweet... It felt so difficult for me to say goodbye.

And Pat appreciated seeing herself reflected in her buddy:

It was very cool because I had been in an experience in the past where the universe beautifully pairs you up with exactly who you need to be paired up with. To choose my buddy, and realize that we both were teachers. To realize we both were athletes. To realize we're both independent spirits. To realize we're both thinkers. And that other part of us is that we go with the flow and have fun and all of those things. So that was very like, Wow! A Mirror....

And my buddy was also someone who looked out for her roommate, which is what I do as an elder sister and a friend, looking out for my other friends and my sisters. So it was just a big parallel there.

There were many other moving and positive accounts of interactions; too many, (as with other components of the training,) to share within the space of this report. I will add two moments that were highlights here, briefly. Christiane was touched when her buddy said to her, on one of their last meetings, "Why don't we just look into one another's eyes?" And Cheryl's buddy suggested that he take her home:

He said to me, "I'd like to take you home to meet my mother." And I just, I wanted to cry... It was the biggest compliment to me; it was almost like going back into the 1930s, and (I thought) something like, "A young man never said that to me before." (laughing) It was so touching.

I knew that he accepted me for who I was. I knew that connection was a real thing. And it didn't matter that he was stuck in the past—it didn't matter. It was just the most beautiful thing that another person could say. It really, really touched me, and I was lost for words. I said, "Oh, Fred! Oh, that

would be beautiful,” and I sort of bumbled my way along, but it really had a big impact on me.

Where a trainee and buddy established a good rapport, this sometimes opened up anguish as well as affection. Maggie had a sense of her buddy’s sadness, and it was extremely painful for her. Several of her visits to him followed times when his son had visited and left, so that he was bereft without fully remembering why.

Angela also had an encounter where she picked up feelings of great sorrow. On the day when the group attended a drum circle, she formed a spontaneous connection with a lady who was attracted by her purple dress. The lady ran towards her and held on to the fabric, seemingly delighted by the color (which happened to be Angela’s favorite). They walked down to the drum circle together, and sat near to one another:

I turned round to look at her and she got right in my face, I mean forehead to forehead. And she just looked at me, and I thought, “She is *so* sad.” I just had this overwhelming sense of, “She is so sad, and I don’t know why I know this but I just know it.” So I was just looking at her and she at me and we were nose to nose. And I welled up with tears because I just was overwhelmed. And she reached around and patted my back... That was very, very intimate one-on-one intuition.

How often do you get that experience? When do you ever put your forehead against another human being’s forehead? I only met her fifteen minutes before. This disease strips all of that away – it strips away all those boundaries.... It boils down to the emotions and the intuition of the disease,

because she had no words. She had no words and yet I knew she was sad and she knew I knew she was sad.

How do we allow more people to experience that? In the day-to-day we get away from emotion... because we don't have that comfort level. She had very dirty fingernails and she had crusts at the edge of her mouth. And I thought, "There's probably not a lot of people who would want to hold hands with her or sit this closely with her." That's the challenge - to get beyond those boundaries that we put up ourselves. All of her defenses were down; and she let me in. So powerful. So powerful.

Donna asked her buddy a beautiful question during their last visit, which ended up revealing some pain she had not expected to find, and which also opened up the connection between them:

On this last day, I was looking at her, and I said, "When I say my prayers, when I'm home, I would like to know: Is there anything you would like me to wish for you?" And she said, "I would like life to be better the next couple of years than it has been the last couple."

And that was the first indication that she gave that there was anything the matter. Because until then, all of her words told me that everything is okay; I get lots of visitors; I don't need anything. But that was the first indication that life wasn't so good. At which point I asked her, "Are you lonely? Even with your visitors?" And she said, "Yes." And then I felt like, "Ahhh. Okay. Thank you."

So then I asked her if I could sit beside her. And I did. And I asked her if I could take her hand, which prior to that, when I held her hand, it felt forced. It felt like she didn't know why was I holding her hand. This time, I held my hand out, and she kept squeezing it. And before I left, I said, "Can I give you a hug?" And she said, "Yes." And I gave her a hug. At which point I said, "Oh, my God, why wasn't this the first thing that I did instead of the last thing that I did?" But she gave such a beautiful, full-hearted, full-bodied hug.

Several trainees expressed worries about the transience of the buddy visits - which involved developing relationships over a few days and then going away again. Mary Jo and Marigrace were both accustomed to building familiarity with elders over a long span of time. Mary Jo said:

Such deep connections cannot so easily materialize without more history, knowledge and time spent between the persons involved. I don't deny that some may have achieved really beautiful moments though.

And Marigrace noted a certain power imbalance in the trainees' brief appearance in the lives of the memory care residents:

There was something about the short-term nature of it - feeling like, "Here we are; and we get to choose when to be here, and we get to chose when to leave..." It felt different from experiences that I have here, (in Seattle) where I see people in an ongoing way and there is a knowing that develops.

But the predominant conclusion was that it was better to have come and gone than not to have come at all. Stuart described his leave-taking with Janet with characteristic respect:

I told her I wanted to go back to Australia and tell the things that she had taught me. Because she was a bit of a teacher. And she says, "What have I taught you?" I said, "You've taught me to be observant. You've looked at all these people that have walked by, all the people we've flipped through the magazines with. And you've told me all about them. About being observant. And being with." And she said, "Oh. Okay."

In the end, Michael whisked by and gave us a two-minute warning. And I walked her down the corridor, and I put her in the seat. And she literally put her hand up, waving goodbye, right in my face. And said goodbye and then just looked away. She made it easy for me, because she basically indicated that she knew I was saying goodbye. And I just felt that she was allowing me to go without too much fuss. She was very gracious in that regard. I enjoyed her company for a spell, and yes, she's somebody I won't forget very easily.

One factor that made leaving easier to handle was that some of the elders were now more motivated to interact with their fellow residents than they had been just a few days before. Sarah's buddy, for example, had previously been staying in her bed and her room much of the time because of a bad back. In the last two days this lady emerged from the room to join in a collective drum circle, and was socializing with others besides Sarah.

Similarly Magdalena's buddy, who had also been largely room-bound, came out and interacted with other people on the last day:

When at the very end, on the last day, Tabatha was actually out of her room, waiting for me in the living room, that was incredible. That was the first time that she was not in her bed. Sitting there waiting, being sociable. I didn't expect it at all, and she was talking about coming to visit me in Scotland.

Brenda summed up how the 2015 group handled leaving their buddies at Autumn Hills behind:

On the second to the last day, members of our groups were asking, "What happens when we leave?" I did not hear any arrogance there. I did not hear any arrogance there. I didn't hear, "Oh, I have done this great work and I am not going to be there." And I personally did not have that concern because I felt like as long as we can have some positive impact we don't need a perfect scenario, we just need do *something*. But I was so struck on our last day how many of the group that had been worried had also had witnessed their buddy really coming out and connecting with the other elders or team members or whomever. I don't know if it was all of them that shared, but many of them had expressed relief.

I honestly did not expect it, and I was fine without it, because I felt the connections were important enough and stood on their own. But I was so surprised at how many of our colleagues had experiences with their

buddies.... We were so worried about this elder, and here the elders were, on their way, making other connections; and it was very beautiful.

A recurring theme in 2016 was that people with memory challenges may or may not remember the details of their encounters or the names of their visitors, but the feeling will stay with them. The group talked about leftover feelings from good interactions as benign “hangovers.” As Debbie put it, “People carry love.”

In 2017 I went back for some brief visits to that year’s training retreat and sat in on another circle where people discussed their buddy visits. They spoke with affection and respect and appreciation, as if sharing stories of beloved teachers, or remembering a meaningful first date. People listened with interest to the accounts of others’ interactions with their buddies. The feeling was familiar, the tone was familiar, and I had a visceral reminder of what was unique about communities of Memory Bridge trainees.

Formal Presentations

In the Introduction, I referred to a few of the ideas from Michael’s talk “Love is not Normal” as a way to explain Memory Bridge. During the five days of a training retreat, this was one of four presentations he typically gave, including at least one story from his own life. These constitute the main cognitive components of the training and its explicit messages. The philosophical underpinnings – the ethic of mutuality and unconditional acceptance for example - are certainly key to Memory Bridge’s purpose, and he tries to approach the same themes from intellectual, contemplative, experiential and narrative angles.

A large majority of participants said that they found these talks helpful. Two people found them too academic in tone and content, and difficult to connect with as a result. Stuart preferred Michael's stories to the lectures, and felt that the language of the talks should be more accessible to ordinary care partners:

The people that need to hear those words are the mums and dads and the brothers and the sisters and the families of these men and women that are going into care. And they need to know that they can, and that they should (hear them). And they're not going, "Hey, maybe I'm the lowest in the pond."

... He's doing something that is so needed. In regards to getting his message out I'd hate for it to come across wrong.

Mary Jo echoed Stuart's thoughts in her evaluation, saying,

I so respect you Michael... However, my education and professional life experiences did not prepare me for some of the intellectual and philosophical content of your discussion. Much of the time I found myself desperately trying to translate the meaning in your message through the choice of your vocabulary.

She would have liked practical information on Validation Methods, along with some role playing. And Greg questioned the pedagogical effectiveness of the talks, even though he found Michael fascinating to listen to, saying, "Even though the talk was very powerful, I think I would have less of it and more direct experience activities."

Most, however, said that they benefitted from the talks, and there were a large number of positive comments about them in interviews. Emma, among others, said that she appreciated the intellectual stimulation. She has continued to refer back to one of Michael's talks on non-verbal communication, remembering,

The discussion around the primary process that a baby goes through, encoding and embodying meaning in their body, and the fluidity of that primary and secondary process. (Hearing about) permeability between the two in dementia was really meaningful to me, particularly moving into the work with movement and dance therapy. That was a really powerful kind of take-away to hold onto. That really brought out the value of anything that's a movement kind of therapy and dove into that non-verbal, creative expression space and the significance of that for someone who is losing their ability to communicate through language.

Many others said that they found the content useful for their practices at the retreats and beyond them. One of Michael's recurring themes, for example, was the value of listening. This topic helped set the expectations for the circles and for interactions at Autumn Hills. Cheryl expressed how the theme impacted other elements of the curriculum:

People were very emotional and very much connected with the person speaking. And I think it was because we were so focused on listening, that we managed to do that. Which is a powerful thing.

Emma also noticed that Michael's talks had helped her to develop a new understanding of listening:

One of the things I most reflected on when I left was that a lot of my way of empathizing with people has revolved around a shared experience... If I hear someone talking about something, and I feel empathy coming up, rather than really staying true to these unknown realms of their unique experience I want to actually map it back onto *my* experiences and relate back a shared bond of experience to tie myself to that person in that moment. Which is actually really not so helpful in terms of being in that space of deeply listening. Because it's taking me away from truly trying to understand and be in their experience in that moment, and it's bringing it back to me.

She appreciated the chance to reflect on,

All these layers of listening that you realize that you are able to dive so much deeper into, the further you go.

Heather found that the talks combined well with her direct experiences at Autumn Hills. She described how they increased her ability to connect imaginatively with cognitively frail elders:

I think the lectures do a really good job of priming us and giving us a lens by which to really see what we were walking into....

Michael talked how we live through that spiritual-emotional connection, and we feed off of each other. ...I imagined, what does it feel to have my cord cut, to not be able to get fed?... I imagined, what would it feel like to be

invisible? What would it *feel* like to never have anyone make eye contact with me?

After the training retreat was over, Heather found that she kept returning to what she learned from the talks, especially the message about listening. She gave me an example of a time when she had put this into practice:

I've looked through my notes, and they have very simple, gentle themes. They say, "Love is listening." How many times I wrote that down, I can't even tell you, like, how can I not remember that? It's like the whole thing was designed for me.

...Okay, the example would be Julie, with a husband who does not understand why his wife cannot remember how to make dinner.... I say, "Tell me a little bit about how you grew up," (to find out) if he grew up in a time and place where his mom made dinner... Every once in a while, I can say, "Can you remember a time when your mom didn't make dinner? Can you remember a time when your mom couldn't remember?" And then we can gently start paralleling those experiences with his wife.

Listening was an important theme for Emily, too - and also one that stayed with her after she left. She said,

I've noticed a difference in myself since I came back. In terms of just small things. Someone's talking to you - just taking time to physically orient yourself towards that person, being properly present, maintaining eye contact, all of those sorts of things.

Others found that the talks validated their previously held practices and beliefs, and put them more clearly into words. As noted earlier, most of the participants already worked with people with dementia from a place of respect; and were already inclined towards a “being with” approach. Michael’s talks supported this. Being validated was especially important for the trainees who were working in professional positions where they had relatively little power, and few (if any) colleagues who understood their way of thinking. Julia, for example, said,

Michael spoke about things that I care about... thoughts that are just forming for me over the past couple of years ... Michael has really established those thoughts ... He is so thoughtful and articulate... about this world and about relating to people. And it was so validating to hear that. Oh, I am not crazy! I am not alone! This is real and this is something I can point to.

Jill expressed a very similar sentiment. She felt,

Just this overwhelming validation that I am doing it right. I have been doing it right the whole time. I can’t even explain to you how huge that is... I have struggled for years with feeling like the work that I do is not as important, I am not as an important a member of the team....and now I am like, “What I do is absolutely as vital as any part of hospice care.” Especially my patients who are in altered states of consciousness or who have altered cognition. Especially those in facilities - that connecting and that being with. Oh my God, it is not an extra, it is not a bonus. It is the whole goal of life!

Similarly, Maeve said,

One of the big things for me was the affirmation and acknowledgment. It's been really important for me; just that acknowledgment that what I'm doing is fine, and it's okay and I can just relax.

Several participants said that Michael's talks provided them with ways of explaining their approaches to elder care, which they had previously had trouble justifying to their co-workers or supervisors. Christiane works in an institution where she is under pressure - sometimes from elders' families - to hurry and to meet practical, rather than emotional needs. She said that following the retreat she was able to defend her approach more clearly, and explain *why* she slows things down. Debbie, who trains professional care partners, said that Michael's philosophy took something she had experienced herself and "eloquently and accurately put it into words. Now I have a tangible concept." This aspect of the training has helped her to advocate more clearly for a shift in perspectives towards elders that she has long advocated; "a transition from being a them to being an us."

Donna explained how Michael's advocacy of non-cognitive communication as a way to dissolve hierarchies lined up with her own experiences in dance therapy. She said, "There is no hierarchy, absolutely no hierarchy, on the dance floorTo have that (Michael's) way of describing things really helps."

Molly explained how the combination of hearing Michael's talks and the Autumn Hills visits has helped her to communicate more effectively with the students she supervises in a nursing home:

Sometimes the students struggle. If they have an assignment they do a good job. Like if they are told that they need to transport someone to the beauty parlor, they do a really good job. But if their assignment is to be on a certain floor and “be with” someone, that can be harder you know; it is a harder concept.

So now that I have gone through Memory Bridge - we went to Autumn Hills and just had to be with people, and I can speak to that experience better and give them pointers. And I go up with them and help them with that part if they need it.

Ryan has also been incorporating Michael’s theoretical ideas into his work. Soon after the training, he gave a forum presentation to residents at the institution where he works, drawing on Michael’s description of dementia as a public (rather than individual) issue.

We have that dis-ease about the disease of dementia, which Michael was talking about. I think that that is pretty profound, because when we talk about dementia and dementia care, so often our focus is on people living with dementia but the fact that we talk about *our* dis-ease makes it about us...

So what I intend to tell the crowd is that most of us, and actually probably all of us if we are honest, has some dis- ease with the disease of dementia and how that shows up in really small and hard to detect ways...Minimizing our dis-ease is such a very important step in providing better care.

In addition to the benefits of particular themes, of validation of their own practices and ways of thinking, and of new ways to articulate values, Susan noted Michael's "beautiful use of language and attention to language." She said that it was a luxury to be able to listen to him, and to be invited to think analytically about words. The contrast he draws between "disease" and "dis-ease" is an example of this. In another presentation, he talked about "letting go" of judgment, "letting in" others' perspectives and "letting be". Elsewhere, as noted in Chapter 1, he used the metaphor of a pyramid to describe the social hierarchies that we tend to be dominated by. To let go, he said, is to free oneself of domination by the pyramid. In letting go we can move, "out of the pyramid and into a dance."

Michael also expressed his love of language through storytelling, which is the next pedagogical component I will discuss.

Stories

The curriculum included stories throughout the five days. Michael told stories from his own life and from his grandfather's life, some interspersed with his more cognitive material, some by themselves. He is a master story-teller, and is much in demand as a speaker outside of the Memory Bridge organization as well as within it. The participants themselves also told, and drew, stories of formative life experiences to one another in a structured activity where they made "I land maps." And the groups discussed two literary stories - the novel, *The Death of Ivan Illich* by Leo Tolstoy and a short story called "A Very Old Man with Enormous Wings" by Gabriel Garcia Marquez. Thus through the course of the retreat the participants engaged with narratives from several angles - as listeners, as readers and as presenters.

I had originally been introduced to Memory Bridge and to Michael through his stories. He came to my Life Narrative class in 2014 and told the history of his grandfather and great grandfather, which moved the students and I to a kind of stunned silence. Like us, many of the trainees found Michael's accounts memorable and resonant. Here is Marigrace, for example:

I was really moved by hearing Michael tell his story about his grandfather.

And that story is one that stays with me a lot... especially the moment where his grandfather was getting up to accompany Michael out to his car....Michael was aware that he wasn't suppose to be out of the house anymore, so Michael rushed out and shut the door - a screen door with a window. He shut the door and was looking at him through the door.

In the interviews they talked about their experiences with stories at the retreats in overwhelmingly positive ways. Magdalena found the literary discussions a highlight, as did Susan. Susan reflected on the discussion of *The Death of Ivan Illich*:

It felt to me like we were in some instances really dissecting the text as a way of dissecting our own experiences throughout the retreat, and that—again, it was not something I had expected to do, but it was something that I thought was really powerful.

On the third day of the retreat, trainees shared their own stories in an activity called the “I-land map”, where they drew pictures or diagrams of key events or metaphors from their lives, and took turns showing the pictures and elaborating on theme in the circle. The day before, Michael had modeled the activity by remembering and describing an incident

from his early life. Brenda talked about how effective she found this, both his narrative itself and the way it acted as a precursor to the I-land stories:

It was about when he was just a pup and his best friend was his dog, and how his dog died accidentally at the hand of his grandmother. Just real vivid detail and what that meant to him, and clearly that is a moment that is real for him... Having him exhibit to us, "This is what I want you to do."...

There was a change after that. He freed us for the next few hours and the next day, and there was this sense of concentration and people were really working on their maps, putting their hearts into it...

It was like every person had something that was kind of a negative and definitely identified a part of who they are.. Because they overcame it or how they continue to deal with it made them the person that is strong and capable of what they are... It was sobering and it was sacred... And some of us talked later, and some of us had not shared that depth with that amount of honesty and emotion even with the closest people in our lives...

If all that is in Julia, then what is in my elder, then what is in my buddy and what is in my beloved or my boss?...I saw in some cases a visible surprise, or like an "Oh!" or a "Wow" or like a hand to the heart - exuberantly - saw this realization. And in others I just saw them act differently and more lovingly and more openly with each other the next day.

Several people expressed a similar idea, and I will include three of the other accounts, because I found them striking and beautifully expressed. Not only did this shared

storytelling create emotional connections within the group, but it also created connections with the people they encountered when going back into the outside world. Marigrace said,

For whatever reason I ended up sharing a lot about being hurt, which is unusual for me. It definitely doesn't come out on a regular basis or even with people that I am friends with here. And then, I also did share some about my relationship with God, and felt like I was able to share about it, more than I normally would, because usually I have that sense of this as not appropriate or of being seen as some evangelical person.

....All of us as humans have been marked or hurt and have had to come through a lot of potentially traumatic situations. It helped me feel like everybody that I look at in this world has that kind of story; but you don't often touch it. A lot of people that I walk by on the street; they have a lot in them that they are carrying.

Julia said that the I-land activity proved a turning point in her relationships with the participants during the training, and similarly that it increased her sensitivity to other people after she left:

We were all just very vulnerable to each other... Something about going through that week, going through the time in the week, allowed for a continual shift in me. I think it was the sharing of the I-land maps that allowed for a shift. And then just going back and back, when in normal life I wouldn't go back; and in normal life, I would not share with everybody.

After leaving, she described,

Riding the train to work. For the next couple of days after being back, it was different, I felt a lot of tenderness towards people about our shared humanity, with people on the train, and also the humanness and vulnerability of each person that I was with.

Heather also showed how the variety of stories and life histories expanded her appreciation for other people:

For me, it was this amazing, beautiful exposure to all these ages, all these venues, all these different people with their different perspectives, and so I'm ever grateful. When I walk into a nursing home now, I look at the director, and I see our retreat. I walk into a sports store, I see our retreat. You know, I meet a first year med student....

Because all these people were humanized to me, it helps you really remember; when I meet people, they have a story. They have a reason they are who they are. I think that it made me appreciate and respect people more.

Christiane's I-land experience also went beyond the circle itself. She found an echo of her story in the natural world:

I had this turtle on my I-land Map, and I connected it to my grandmother, somehow. I don't know why. I have this connection with my grandmother and the turtle, and my little Whiskey Island Map. And then the next morning, when we walked down from meditation, there was this turtle

crossing my way. This was very special. It's such a big symbol for me for my safe place, for my allowing myself to be slow when I want to be slow.

She noted the importance of storytelling for caretakers in particular:

They also need a space where they can talk about their own story and not be interrupted. And this is really important... Every person has a story.

Magdalena expressed a worry that the I-land exercise ran the risk of making people *too* vulnerable. Fortunately this did not seem to happen. Everyone who talked about this particular storytelling exercise described it as a positive experience. Gina, for example, said that it had a liberating effect on her. She was both touched by others' stories and proud and relieved to have overcome her fears before she spoke. She conveyed her appreciation for,

The stories of people's lives and the impact and trauma that shape them and make them who they are. It was down to the individuals to share as they wanted to; there were many emotive times. I was extremely nervous about personal sharing with some of the shame. It was hard but felt very liberating.

Down time

A large number of trainees described the stretches of time in between scheduled activities as important learning experiences in themselves. Ryan found the training retreat "very intensely communal". He thought that this was especially true for people living in the main building rather than in the yurts, because of their easy access to shared spaces. He listed some of the things that made for close bonds:

It was the intensity of the buddy visits, and our anxiety and emotional strain of wanting to dwell in our dis-ease and expectations. It was the group circles and the outpouring of emotions, the lack of sleep, and meeting new people, and trying to figure out where you are in this group.

We didn't close the circle and go to bed. We would sit up and process a little bit. And in the early mornings I would get up at 5:15 to exercise and then I would come back and make coffee for everybody. And it was just like being in a family, because you see the person wake up and you see them go to bed... Conversations - we would go on walks and we would process things. And when someone was upset about something, we would process that.

Mealtimes and night-times also gave people a chance to talk one-on-one with others. Julia said,

I am so much more comfortable one on one with people. At meal times, if I was just sitting next to someone, then I can just talk with them and get to know, share a bit of myself with them. I think that that intimacy was brought back with me to the group so it allowed me to be more comfortable.

Molly noticed how focused and present the trainees were during mealtime conversations, in contrast to her everyday life:

I don't know if this is a New York thing - because New York can feel a little different than other places - but you can be with people but not really be with them. Everyone is on their phone.

Pat especially appreciated the opportunity to talk with, listen to and process with people who had been live-in care partners, as she had. She shared a yurt and conversation with Sarah.

She's into yoga and holistics and organic stuff like I am. And for us to get a chance to talk - where I've been out of the direct role, so to speak, for almost two years, she's been out of the direct role I think maybe four or five years. But, the fact that she's still processing. I haven't got to that point, because my dad is still here, thank God.... She was a care-giver for two people twice. And then you're finding your new normal, and all that that entails.

.... Memory Bridge was a way to cathartically release. Listening to Carolyn was like listening to myself. You know? And talking with Maeve and Sara and everybody, it literally was - "Okay, okay: there is a generalized theme here that we all have gone through." And each one has it own little uniquenesses, and yet to be able to be a support with somebody, that's great.

But also to just be in face-to-face and say, "You know what? Right now the support I need is to support myself. Ask for support." And it's okay. And it's not judged.

For Heather, there seemed to be "an invisible hand" which guided her through all the informal activities, as well as the scheduled ones. She told me about several instances of serendipity. The first happened shortly after she had arrived and settled into her room. She went for a walk with a few others and they ended up sitting together in the meditation hall:

All of a sudden Christiane said “Would you like to hear my mantra?” And so she sang her mantra, and we all sang, we all followed her in saying her mantra. And then I said, “Well, would you like to hear my mantra?” because I went to Asia, and I studied Buddhism for a while.

When we were done, Christiane said, “You know what?” And we said, “No, what?” ... There were titles over our doors in our dorm room. And the one that I sang was over the door frame of my door. And... the one she sang was the title over HER door. So, for me, the experience got really interesting about an hour in.

I didn't even know what my mantra was called. I mean, I had no idea. And she knew how to read it. I don't even know how to read them.

Several people in 2016 looked back on times of laughter (and sometimes whisky).

Greg remembered the informal gatherings in the yurts:

People let their hair down. They lose their presentational personas and kind of just talk about what they're thinking and doing and it's funny - loud, raucous laughter. And Michael joined that on our last night, after he told his story, and we all gathered.. And he let his hair down too. It was great.

Christiane said,

There was so much energy there after three days in that group. And we had just so much fun, you know. We were like little teenagers giggling around, and laughing ... And Stuart almost died of laughing

As with the gathering described in the “Circles” section - where people worked through the differences in talking styles - conversation in these informal groups sometimes enhanced communication in the circles. Magdalena described how this happened at an impromptu party, which Michael attended:

I think it actually seemed like a good opportunity to maybe bring up some of the things that had been (on my mind), mostly for myself, but I remember that Stuart also had some thoughts that he wanted to share. It almost felt as if the slate had been wiped clean.

A few people got together in circles or interactions that were nature-focused or spiritually oriented. Donna described the following experiences in 2016:

There was a group of us that sat outside the first night, and there was a chant circle. And we got together three nights, and that was very wonderful. Watching the fireflies was amazing....

Such a wonderful inter-generational or cross-generational experience. The last night Emma wanted to do a women's solstice circle, and so there was Emma and Heather and Emily and Maggie and myself. And that was very sweet, very intimate, and contributed to my feeling of - just so lusciously intimate and soft and safe.

Emma also found the informal gatherings to be high points of the retreat:

There's just lots of joy. There's the connections, the conversations - particularly at the women's circles that we would have in the evening after

session. The moon rising and all the fireflies were lighting up around us, such magical times.

Jill described receiving a gift from Angela that supported her meditation practice after she left the retreat:

Angela had talked about that she sees colors around people. And she talked about that during her I-land map sharing. I don't see colors around people. So when she said that I desperately wanted to ask her, "What do you see on me?" (But) I would never ask her to perform a circus trick for me.

The last night she had this clump of little necklaces. They were these little glass hearts on strings, these little colored glass hearts on strings... And she gave some of us that she had spent enough time with... she gave us each a heart of the color that she saw around us.

The color that she gave me was gold, golden yellow.... I have used that little gold heart as an anchor for some of my meditation, and this idea: I have this light and it can be big and very bright and very warm or I can dim it down if I need to. Things like that were helpful revelations.

Group Activities Initiated by Trainees

Participants brought their own ideas and activities into the group - drawn from their experiences as care partners, trainers, administrators or artists of various kinds. These activities were primarily non-cognitive or arts based, and provided a contrast to the more sedentary talks and circles and stories.

Donna brought an Octaband with her in 2016. It is her own creation – an octopus made of fabric – and demonstrated its use for us. Each person took one of the tentacles to pull or shake so that we were palpably in touch with one another. Magdalena drew on her clowning experience for role-playing games, which were silly, fun and active. They got all of us running around the room and moving in various absurd ways. Emily taught us some wonderful and simple songs, also silly, with choreographed movements. As a PhD student with a focus on arts approaches to dementia care she was especially attentive to these aspects of the retreat:

One of the things I felt that were little jewels of treasure were the different arts practices that people shared.... Everything from the impromptu singing that we had at the care-home, the drum circle, through to the Octoband, through to the theatre games, through to the dance and the poetry - there were so many little nuggets of the arts which were shared throughout the week....I think those are things that you take away with you, being able to crystallize, potentially, what words can't.

Music and drumming proved to be good points of connection at Autumn Hills, helping Emma, for one, to feel more at ease on her first visit:

One of (the trainees) struck up a conversation with someone, and somehow it just immediately translated into “How about this song?” And the next thing you knew, everyone was in a sing-along when we walked in. And it was just so full of joy and actually I had very little nerves at that point at all... it made it a really nice, lovely, easy transition into meeting my buddy.

Both years, a former Memory Bridge participant called Kareen King volunteered her time to lead drumming and singing at Autumn Hills at a large collective gathering. She led the group in popular songs and then handed out percussion instruments and encouraged everyone to drum out rhythms. For Gina, drumming at Autumn Hills with residents and other trainees was especially memorable:

The drumming session - the energy! At one point, I felt I was out of my body looking down on the group and feeling this real sense of connection, magic, togetherness - a real connection of loveliness. It was wonderful.

Jane's tendency to select people with arts backgrounds (which I mentioned in Chapter 3) thus proved enriching. It meant that participants were able to add non-cognitive activities to the story-telling, meditation and eye contact (which were already established parts of the curriculum). In 2015, Carolyn, who works in theater, shared a performance piece she had written - an allegorical story about dementia. In 2016, Donna wrote a "dancing poem" about dementia. Michael asked if she would dance it for the group:

That was something that would ordinarily have sent me into paroxysms of anxiety. And I felt safe enough, I felt heard enough, that I could do that. I was willing to do that, and the experience was a major shift for me.

Because I felt the shift from words. Different people had done that at different times, whether it was Emily singing or doing a bungalow movement, or Magdalena doing those things that she did. They were shifting the ways of knowing what we know. There's very few circles where those parts of myself are seen.

That (non-analytic expression) feels important to me in the work with people with dementia. Because they have access to that; that's where they excel. And so, it feels important to me to be able to share that with colleagues and also with people with dementia.

Emily read out the poem as Donna and Emma danced outside to accompany it one evening. This was a highlight for Emma, as well. She had been aware of Donna's work as a dance therapist before she came from Australia to the United States, and had been thrilled when she realized that Donna was to be one of the other trainees:

It was amazing to get to connect with Donna, and a real privilege and honor to get to share the expression of her poem in that way - it was wonderful.

That was a really big treasure I will cherish big-time.

Sarah had some expertise in yoga, and she led the 2015 group in daily exercises. She also led trainees in a song on an early visit to Autumn Hills. She said that this was unusual behavior for her, and she associated it - along with some of the other artistic expressions of trainees - with the accepting atmosphere of the retreat:

Even though I enjoyed the singing I still felt fairly new to the group, and this isn't something that I would spontaneously do. So I feel like I revealed myself. I was moved to reveal myself and be vulnerable and to sing in front of people and to share my enthusiasm

....There was another moment, and I think it was after dinner some time.

And again it involved singing. Walking into that room next to the dining room, Jill and Ryan were singing. She was playing the guitar, and that was

nice... Looking over, Maeve was doing this beautiful dance in the corner. And it was just this moment where I felt like she was revealing her vulnerability about herself. She was moved to move, and she said later that she doesn't normally do that kind of stuff.

So it felt like this environment where these things could come forth. I had this feeling of, "I am among openhearted, accepting people." And that was the environment that Michael cultivates; and everyone else does their part. It was the people, and feeling like I was in a space where anything was possible, and anything was welcomed.

Eye contact

As part of the curriculum for both years, Michael had participants get into pairs, hold hands and look into one another's eyes for a few minutes. Molly described how this worked for her, and why it has proved helpful in interactions with elders:

Being really focused on that other person, having that really concentrated eye contact - it can be awkward when you don't know someone. And that is the whole point. But the people with Alzheimer's and dementia, really they know, they know, they can feel that you are with them when you make that eye contact.

She has incorporated this activity into her training for young volunteers, aiming to give them a visceral sense of paying attention and being paid attention to themselves - "to show how you feel when someone is looking at you."

Emily approached this activity with some trepidation. She attributed her fear to a British culture of reserve:

I was like, “Oh, that's going to be really awkward.” But I had the pleasure of doing that with Christiane. And she was absolutely marvelous. She had got a huge amount of professional experience, the likes of which I can only dream of at this stage. And so she brought such a calmness and a serenity to that experience, such a genuineness of emotion. And a real giving-ness.

.... I thought, “As we go through this exercise, the longer we're doing it the more it's going to become awkward”... And actually it was the complete opposite. It was almost as if the longer you sat, looking into someone's eyes, the more comfortable you became.

A week or two after the retreat, she and her housemate saw people staring into each other's eyes on a television show. Her friend asked her whether she would be willing to do something like that. She answered,

If you'd asked me that question two weeks ago, before I went to the retreat, I would have been one of the people awkwardly being like 'What's happening here?' But now, I absolutely would.

A number of other trainees also remembered the eye contact exercise as an especially moving and meaningful activity, including Angela, who said,

It was like meeting someone right in the middle - being able to give and being able to receive... We had these enormous, enriching, overwhelming

experiences that put us in a place where we were able to be with, and get into the “Valley of Awkward” - knowing there was a way out of it.

Susan recounted a time after the retreat when she could draw on this memory as a resource.

I have, since coming back, found myself being much more intentional and much more aware of looking people in the eye; certainly in the programs that I do, when I'm talking with people. I mean I've always tried to look people in the eye, because I think that's really important, but now it's at the top of my mind. Whereas before, perhaps it wasn't quite that way.

When my husband and I went to the store, there was an older woman who was at the check-out counter, and she seemed kind of frazzled. And I just thought, “Well probably nobody has actually bothered to treat her as a human being, as opposed to a robot who's checking people out”. And so I looked her in the eye and smiled and it was amazing. It was as though the sun had come out for her.

CHAPTER 4. WHAT PEOPLE TOOK AWAY

There is not a thought, or a moment in my work where Memory Bridge is not there. It's right there all the time, because it's the accountability model. It's "Am I Doing It Right?" And before that I did not have a lens to decide if I was doing it right.

Heather, 2016

In the last chapter I took each element of the training curriculum separately and described participants' responses. In this chapter I will write about what people took home with them from the retreat as a whole. Although the interviews did not follow a fixed set of questions, I was interested in what trainees remembered most readily and vividly, what they said about their overall impressions, what suggestions they had for improvement, and what, if anything, seemed to have changed for them as they returned to their everyday lives. I will begin with some summarizing comments from participants about the way the pedagogical strategies acted in combination – how they reinforced, echoed, complemented or balanced one another. I will go on to discuss three recurring (and overlapping) themes that people brought up as benefits from the retreat – relationships with one another, validation of their perspectives on dementia, and a focus on listening. I will look briefly at the challenges of caregiving in the “real” world, including medical institutions, and outline some of the ideas people had about how to bring Memory Bridge’s principles into these settings. I will write about changes (if any) that they saw in their interactions with elders and others after the training. I will end with suggestions from trainees and with a few further summarizing comments.

How the Activities Reinforced One Another

As is clear from the last chapter, the pedagogy at a Memory Bridge retreat was designed around a combination of activities. It incorporated lectures, sharing in circles, art, movement, storytelling, drumming, song, nourishment, play, eye contact and meditation – in short, a range of human experiences and modes. As is clear from this list, the training engaged the intellect, but intellect was only one of many of its components. This reflected one of the organization’s core messages: cognition is not the only measure of a human life. People have value with or without memory or verbal skills. People with dementia have value. Michael considers that most existing human societies have a lopsided notion of what is good and important – giving undue importance to what he calls “the calculating mind.” The calculating mind measures and compares people and gets in the way of community. It is as much a source of harm as a source of good. Those who have lost the ability to measure and compare, then, can model and elicit ways of being that we neglect to our detriment. They are teachers because they can redress the balance.

Ironically, this itself is a theoretical idea, and Michael included lectures as part of the curriculum – providing abstract ideas to question our over-reliance on abstractions. Most trainees said that they found these ideas helpful; they framed and justified the other elements of the retreat.

Several participants noted the way the different components reinforced one another. Julia, for example, said,

It was a dual process, or maybe a triple process, for me at the retreat. There was this didactic part with Michael, and he would be talking about empathy, compassion and being with others. And there was the group part where we

were literally practicing with each other. And then there were the buddies. So there was the intended application of the practice of compassion and empathy and being with others - with buddies with dementia... threefold opportunities to learn and integrate.

...It would not make sense to me to be growing my empathy muscle only toward people with dementia. It was going back and forth with the group, people with dementia and myself.

Brenda, Julia, Pat and others noted also how the retreat unfolded over time across the five days. Brenda appreciated the way Michael had paced the activities:

I was so struck throughout the whole retreat how thoughtful and conscientious it was. That it was almost like a boot camp situation. We were all together; and by day two or three, a bunch of us were irritated with others. And then by the end of day three there was this big release - which it seemed was timed perfectly with the I-land map.

It was such a thoughtful (design). This is how people process.... There was something later in the week that Michael said - "Part of the Memory Bridge retreat is also to create a space that is protected enough and secluded enough so that we can truly be there." I really saw that. There were a couple of my colleagues, in the first couple of days; you could see they were still in their minds - that they were still back in the daily world, thinking about, "What am I going to take back to my boss?" or "I hope I didn't forget to tell them to do that thing..."

At some point I felt like we were all truly present and able to receive. The whole format and the structure was so intelligently built - to truly lead people along, and know that they are not going to be present at the start, or not all of them. The different sections of the retreat when Michael was sharing his thoughts or perspective or opinions - it wasn't really a workshop, it wasn't really a lecture. In the Jewish tradition there is this thing about sitting at the feet of the Rabbi - it felt like that. But I was surprised how often it was *not* a free-for- all...I thought that was also really striking, that Michael had these dedicated periods of, "Okay now there will be some discussion but then I am also going to share my worldview." But it was not arrogant either. I was stunned at how thoughtfully it was all put together.

Naturally enough, in this varied group, people had different preferences as to the balance of activities, and as to the worth of each component. Most agreed, however, that the interaction between the different pedagogical elements added value to each one.

Community: Relationships and Interactions Among the Participants

In Chapter Two I described how participants were selected for the training, and I gave some examples of the experiences they brought with them. Michael envisioned groups of people forming connections where they could learn from one another and have a visceral sense of what it is like to belong in a community. When they looked back on the retreat in their interviews, almost all of them commented positively on both these processes. They referred to the relationships among themselves frequently and with emphasis. They also retained the relationships after they had returned home.

As I noted in Chapter Two, there were a number of factors that enhanced cohesion among the group. First, they shared an orientation; they considered it possible and desirable to connect deeply with the elders at Autumn Hills and beyond. Second, the selection process favored empathetic people. And third, the curricular activities - like story telling, circles and eye contact - enhanced their intimacy.

The trainees built friendships in formal and informal settings. In the last chapter I wrote about the circles and also the stretches of time between planned activities. Greg refers explicitly to both of these when he looks back at the connections he made:

I strongly remember those indelible characters—six or eight folks I would be delighted to see anywhere.... Each experience had its own trajectory when I discovered one person or another. Stuart, because we were rooming together and so we could sit up and talk late at night. Donna, because we did the toe-to-toe, knee-to-knee thing together (the eye contact exercise). It was interesting; I felt we became friends in that time; we were always friendly before, but I felt kind of a deep connection with her.

Cheryl saw the circles as primary, saying “I think in the circle is where it began. With each other, we let our guards down, and we opened up.”

Cohesion was a gift in itself, but group interactions also led to other kinds of learning. As Natalie watched other trainees interacting with elders, she was able to see possibilities for the staff at the institutions where she worked in Australia. She was impressed that this range of ordinary people could make a difference over a relatively short stretch of time:

We visited them for five days. That's it. The differences we saw in those people in five days were phenomenal....

I've been doing this for years and years. I've felt for a long time in the aged care environment that I've been staring at blank faces (among other health care practitioners). And I've been thinking, "Really? Am I wrong about this?" People don't want to hear it. They think, "It's just too hard." I came back and went, "No - it's really not too hard! This can be done."

The thing that was new to me was seeing a diverse group of people, and a diverse group of people with dementia, and *everyone* could do it. Every single person who came on that retreat was able to connect with other people with dementia that they had never met before. Everyone. Anyone can do this... No one was wearing any super-hero cape there. We're just human beings who cared. It was seeing other people's experiences with their buddies that was more powerful to me than my own experience.

As I noted in earlier chapters, Natalie already practiced Memory Bridge's ideals in her own interactions with elders. This was a wonderful example of how being in the group enabled her to learn something about *others'* interactions - something that could be easily applied in her own professional context.

Maggie also learned by example from listening to and watching the people in the group. In an email she told the others how their models of dementia care had sustained her as she went through her medical studies:

I just got off of my surgery rotation, which has been one of the most

challenging experiences of my life. The high-pressure, high-stress environment of surgery is dehumanizing for patients and providers alike- and it is no secret that elderly folks with cognitive decline suffer the most when being shuttled in and out of the hospital. Seeing our amazing Memory Bridge family exemplify the most important ways to care for the human spirit has rejuvenated me, and reminded me what is important- and how I want to bring love and listening to my practice for every patient, and every day. Thank you, thank you, thank you for reminding me, through your examples, how I want to live my life caring for folks with dementia, as well as all of my patients, colleagues, family, and friends.

This week I return to Martha's Vineyard for more focus groups and exploration of the challenges faced by Islanders living with dementia- and I will be sure to bring all of my love and all of my listening that I've learned from you all.

Trainees stayed in touch after they left, sometimes through one of the group Facebook pages that Michael set up, sometimes through email, sometimes in person. For example, Stuart visited Mary Jo and she showed him around the institution she had initiated - Stone Lodge. Ryan and Jeanene were able to work on a project together. Ryan appreciated the chance to combine forces with her:

Jeanene and I... are working on creating a program that will be endorsed by the Dementia Action Alliance... It can be done elsewhere and can be used for research and communication and for reducing isolation for people with

Alzheimer's. There are things like that that would never be happening if I hadn't met Jeanene.

Listening

Michael feels strongly enough about listening as the core of Memory Bridge's message that he named his second documentary *Love is Listening*. The topic infused his formal presentations, it infused the group norms he aimed to establish in circles and it infused the kinds of interactions with elders that he advocated. It was central to the training sessions, and participants took it to heart. Although I discussed it briefly in Chapter Three in the section on Formal Presentations, I return to it here because it had an important impact on the trainees.

Many of them said that the retreat helped them to listen more consciously and more skillfully, and that this was important in all their interactions, rather than just in dementia care. Donna said in an email that she was listening to her husband "with much fuller attention". Cheryl applied it to her teaching. She said,

What can I tell people? What can I teach people? I see that the whole key of what we did was based on better listening skills...To slow down their busy lives and take time out to stop and smell the roses along the way. If you just say that to somebody, it doesn't make a big impact. It's like: "Oh, yeah, I'm a good listener". But it was only after Memory Bridge I realized how we don't do that. How we're so busy with our own agendas. Even though we think we're being good listeners, and we think we're doing our job as well as

we could, that week really enhanced in us what our true ability is with this work.

....I've been working with my class in circles. Because they have desks, we call it a "squirele" We put our desks in a square circle. But it's been really good. I'm getting great feedback from my students - of them really appreciating that, because we can all see each other better. And then when one person speaks, everybody has to stop and look and listen.

Michael interprets listening broadly, as attention in all its forms. This is clear from his *Love is Listening* movie, where one of the expert "listeners" he films and interviews is the percussionist, Evelyn Glennie, who is profoundly deaf. Listening includes touch and sight. I learned from Marigrace that it can even include taste. She described an incident, before she came to Memory Bridge, where two elders taught her about new ways of giving attention. She was doing arts activities at a memory care unit and a woman approached her:

She ended up lifting up my hand and trying to bite down on my finger... I wanted to pull away. So this other woman with dementia said, "It's okay, don't worry. She just wants to know that you are really *you*." And I was like "Wow, what a lovely example of extending compassion and empathy to another person's experience!" Instead of saying, "Oh yeah, that woman is weird," she was like "No, there's a reason that she's doing that." And you know how clinicians talk about behavior as communications? I felt like the other woman with dementia really got that; so intuitively.

Greg said that the training had increased his sensitivity to what may or may not be non-verbal signals from his wife, Cathy.

I think I'm more open to thinking of almost anything that happens as a communication... For example, Cathy makes repeated motions with her right hand, and I thought that was a kind of palsy. But I think maybe - partly (because of) the film, partly some of the experiences of the retreat - now I treat that as a signal. And I signal back. And I'm treating more things that way. As though it's an effort to communicate or relate. It may not be. It does no harm to treat it as though it were. And I think it does some good.

Emily described a visit with her grandmother. She explained that not just the interaction but her *perception* of that interaction reflected what she had learned from Memory Bridge. They had held hands for a stretch of time one afternoon, while her grandmother alternated between dozing and waking:

If I'd just had that interaction with her before Memory Bridge, I think I would have thought, "Well that was good for me... but I would have probably thought, "Oh, but she didn't get anything out of it because we didn't really talk about anything"...

I felt it actually did make a big difference... we had that tactile connection and we were engaging in that sense of togetherness by holding hands.

Listening goes in more than one direction. Feeding the feeders reflects a necessary balance. Michael designed the retreat activities so that care partners would listen to one another in the groups, would listen to themselves in meditation, and would thus be emotionally (as well as physically) nourished to the extent that they were free to give full attention to people with a dementia diagnosis and others. Magdalena said that after leaving

she had continued the practice of listening to herself and the people in her life. She saw the Memory Bridge retreat as instrumental in this process:

I feel that I'm listening differently. I'm trying to pay more attention, both to myself and to people coming to me with certain things they want to talk about. Trying to give - not necessarily *more* time - but the time I give is a hundred percent and not just rushing through things.... Before I came, I knew that that was something I was really needing to pay attention to as well. To myself, to my family and to (parts) of my personal life and to my colleagues in terms of the things that they need.

Donna also described how the balance between listening and being listened to worked for her. Being heard by the group brought her peace so that she was more able to be attentive.

This was an extraordinary experience, and I feel a sense of calm that I'm not accustomed to... It was listening. Five days of listening was a pretty wonderful practice... Learning how to listen by listening. And by being listened to.

To illustrate her increased listening skills after the retreat, she described a conversation she had had with a young man.

He said, "Oh, you have to smile." And I said, "You do?" in a questioning tone. And he said, "Yes. No matter what, you have to smile." He said, "You have to work at it."

And then he went on to explain. Everybody else had left, and he was just talking to me. He said, "My father died," and I acknowledged that. And he said, "My mother died." And I said, "Yes", and I could see he was getting a little teary. I said, "That must be really difficult for you; you must really miss them." He said, "I do", and, "You have to smile." And I said, "You have to work really hard to be positive so you don't get dragged down." And he said "Yes!" It was such a beautiful sharing.

I felt that all of that happened because of all the listening I did within the group; that he could go down and down and down.

She also said that the experience of being listened to herself had made her more expressive:

I felt as though I was sufficiently heard that, over time, I began to take more and more risks in what I shared and the way I shared.

Jill also discussed the ways expression and listening reinforce one another.

Authentic expression is a risk, and it also conveys respect. Her buddy at Autumn Hills shored up her belief that being honest is essential to communication, just as listening is, and she felt heard by him on more than one occasion. She saw this as one of the core lessons she took from the retreat:

Another thing that I took away was about authenticity, honestly and authenticity. Sometimes you think it will lead to division but it actually seems to lead to deeper connection...

There was one time when I was sleepy; my attention waned and it washed over me. And he said, “You are tired.” I almost lied to him. And I stopped and took inventory and said, “Yes I am. I went to bed way late last night.” Then he was like, “I went to bed late last night too.” And it went deeper because I validated that he could see me accurately. And he really could see me very accurately.

“I didn’t feel like the crazy person on the sidewalk”: Validation

In Chapter 2, I described the way Michael and Jane selected applicants. Given this process, it was perhaps inevitable that the people who attended the Memory Bridge retreats already saw value in connecting with elders who were on the dementia journey. The training resulted in a few dramatic shifts in perspective, as we will see later in this chapter. But many of them had been communicating with elders in respectful, empathetic ways for years or even decades, and thus had much to teach one another, myself and Michael and Jane as well. What they took from the retreat was not so much a new understanding, but new ways to frame it, and reinforcement of the positions on dementia that they already had. Several people said they had increased confidence in their practices, and a new willingness to go against prevailing medical norms. This was a recurring theme. As I noted in the section on “Formal Presentations” in the last chapter, and in the “Relationships and Interactions” section in this one, validation was an important part of what people took away from the Memory Bridge training. Even people with many years of experience appreciated Michael giving them words and metaphors with which to justify their chosen ways of interacting with elders. They also appreciated watching and talking with participants who

had similar values to their own. Emily, for example, felt shored up by meeting other people who could envision better ways to work with dementia:

One of the things that I found really rejuvenating was to be in an environment where you could be an idealist. You could dream about making change, and you could openly say, “I just want to make a difference to others.”

In a circle early on at the 2015 retreat, Natalie said that she had been expecting a manual from Memory Bridge. She thought that she needed one to remind her of what to do once she got back to work in Australia. “The manual” developed into a frequent topic of circle discussions. As the week progressed, there came a moment when she realized, “Hey, I actually don’t need the manual. I am the manual.”

She felt the power of *being* the manual rather than needing one as she started to talk to people after the training. She was able to meet with the Director of Chaplaincies of PresCare, a non-profit organization in Queensland. He had never heard of either Natalie or Memory Bridge before, but by the end of that one talk he was convinced. He made plans to incorporate Memory Bridge’s approach into the training for chaplains, and “to change the whole culture of chaplaincy”. She was also planning to run a three and a half day Memory Bridge training, and to give a public showing of the movie, *There is a Bridge*.

She explained that although she had never lacked either confidence or a belief in the importance of communicating with elders, her conviction about what was possible in her work had increased as a result of the training:

This can make a genuine difference. Memory Bridge can make a genuine difference. This is not something I've been romanticizing. This is actually real. There are so many people who see people with dementia as essentially a lost cause.

It's not that I suddenly saw that people with dementia have capacity - because I already believed that. But that belief of mine had been borne out (by the training) to be absolutely true. Part of it was being in an environment where other people thought that. I didn't feel like the crazy person on the sidewalk.

I quoted Jill in the last chapter on her sense of being validated through Michael's lectures. It was a topic she returned to several times in her follow-up interview. Like Natalie, she came away with increased confidence in "being the manual" - in the value of simply being present rather than following a set of procedures. She was able to pass on this validation to others in her place of work as well:

Social workers in my office are in two camps. There are more case management, task oriented "do things for you" (people), and there is a camp of those that are more qualitative. That is the "Be'ers."

One of the Be'ers came up to me and asked, "So how was the conference?"

I put my hands on her shoulders and I said, "We are already doing it right."

And she was like "Really?" I said, "Yeah, and we will talk more."

Shortly after the retreat Jill – who is a music therapist - visited an elder but forgot to bring her guitar. The interaction added more strength to her conviction that “being” was more important than “doing”:

I drove out to see him. He lives in an assisted living facility and as I got there, I realized I had left my guitar in the office and I had taken it out of my car because it was hot. I was like, “Oh my gosh, I was suppose to bring music to him!” And I thought about Memory Bridge, and I thought that is not what I bring to him. I bring *me* to him...

He was lethargic and hurting. We ended up visiting for thirty minutes. It was great, he is an insightful guy and he comes in and out of the past and present. And he kept thinking I was the nurse.

Jill explained that she was more of a counselor than a nurse, and that she didn’t have anything to offer for the pain; but that she could go and get a nurse if he needed that. “And he looked at me and he said, ‘Really, no offense to the nurses but sometimes talking is better than medicine.’”

Carolyn also said that Memory Bridge echoed thoughts and principles she already had, and that it challenged her to build on them. However, she expressed more skepticism about translating that challenge into everyday practice:

I came to Memory Bridge with a lot of the perspectives on the elderly and dementia, and the capacity for personal connection with people with dementia, that I think Michael wants to share. I mean I came with that. (But) it challenged me to think about my own preparation as I step into

relationships with people with dementia – or with anyone – in terms of grounding and centering myself. To recognize that it's really central to truly focus on the other person.

On the other hand, I felt a little bit like... if I have to meditate for forty-five minutes every morning before I can go see somebody, I'll never go.

She went on to say that she still felt that Memory Bridge had made a difference to her:

It changed me, in that it deepened my relationship with my mother and gave me a new perspective on the time I have left with her. I don't know that I'll be a Bridge to anyone but her, but for me, that's enough.

I will conclude this section on validation with two examples of times when participants were able to draw on Memory Bridge to reinforce them in difficult situations. In both these incidents, they found that the training had given them increased courage to act on their own convictions.

The first of these stories came from Christiane. As a physical therapist, she has to make moment-by-moment decisions about how to touch elders. Memory Bridge enabled her to be more assertive about respecting their choices and boundaries, even when their relatives disagreed.

I already had a pretty respectful way of dealing with my buddies or my patients. But also...my goodness... sometimes you run around, and you don't have so much time, and you don't want to go so deep into all that talking and thoughts and wherever they go. I feel a little bit more patient, and maybe I spend more time with listening

I know that my role is to protect and give a safe place to my people, so if too hard (physical contact) is not a safe place, I won't do it, and I can explain it to any daughter or son... Sometimes family puts the most pressure on me - how the mother has to function again. I'm very clear about that and I don't allow them to pass on their pressure through me onto their parents. ...I'm far more clear about this attitude, and that it is the right attitude.

She was working with one elderly lady whose hand was acutely sensitive:

It was completely swollen and painful. She didn't want to be touched at all, and I was very careful. And there was the son who came, and he tried to explain to me that he has found out that if his mother suffers a lot of pain in this hand she will recover and be able to move it. Because of the pain she can feel and find her hand, and this will help. And I said "No."

And I felt so strong to say, "No. That's not the way we do it. It's not right."

And I felt clear about that... I said, "No. This is just human. This is something you don't do - especially you don't do it to your mother." I felt really clear about that. And immediately when I met the doctor who was taking care of her, I said that the son was hurting his mother, and I wanted him to explain it to him too.... I said, "I protect this old woman. This is my only job here - to protect this lady. Even if I have to protect her from her own son".

...Before (Memory Bridge) I would have felt maybe angry or desperate or useless - all that. But I felt very clear that I'm the safe place now for this old

woman. I have to be the safe place and be clear about it. I feel stronger with this attitude. To put it that way, and to express myself that way.

Maeve also acquired courage from the training. She had returned to her dance therapy work at an aged care facility in Australia, and there was an accident:

During one session a gentleman fell out of his wheelchair onto the floor and he knocked his head. I called for one of the nurses, but the man was all tangled up in the wheelchair and in the chair next to him.

So I did something I would never have thought to do before. I just sat down next to him. The nurse and assistant were trying to help him, but they were working very quickly with him. Anyway, he just reached out his hand and he said, "Hold me." I held his hand, and that felt right. Just to be there, and not say anything but just hold his hand while they were trying to get him free. I think I was being a calming presence for him while all the flurry was going on around him.

That was something I wouldn't have done before - I wouldn't have had the courage to do that. I would have just left it to them to do it. They're in charge.

In both incidents Maeve and Christiane felt increased confidence to act in spite of the way things were usually done in their places of work. Christiane had to actively resist pressure from elders' family members. Maeve had to take an initiative in spite of the hierarchy in the memory care unit, and in spite of the risk of being perceived as inappropriate. Both women were highly empathetic, respectful and sensitive to elders with

dementia before the Memory Bridge training. The training enabled them to express these qualities more openly in the face of prevailing medical norms.

As is clear from these last two narratives, most trainees had to return to social environments where the values and practices around dementia were different from those shared by the Memory Bridge organization and the retreat participants. So I will now turn to this meeting of worlds and worldviews. In the next two sections I will look at participants' practical suggestions for family care and aged care establishments. I will begin with their acknowledgment of the challenges, and move on to the plans and projects they discussed after leaving the retreat.

The Personal and Professional Challenges of Dementia Support

Many of the trainees talked about the practical obstacles that can get in the way of taking a respectful, empathetic approach with elders at home or in institutions. Memory Bridge emphasizes "being with". But cognitively frail elders, particularly those who are in advanced stages of dementia, require "doing for" as well. Many of them need to be bathed, dressed, toileted, diapered, fed, transported from one place to another and soothed in the middle of the night or the early hours of the morning. Pat's father used to wake up and wander out of his room every couple of hours during the night when he lived with her. There were relatively few home care partners at the retreats compared to those employed professionally, but these few had a lot to say about the difficulties they had faced. People who worked in aged care institutions also noted the difficulties for the nurses, aides and staff directly responsible for meeting elders' practical needs. This is

reflected in some of the literature on dementia care, as I mentioned in the Introduction²⁸. The ideals of quality, respectful care often run aground against inhumane workloads or family isolation.

Pat had been an at-home care partner for her father, and she was acquainted with several other women who had taken sole responsibility for an elder for years. She explained the challenges:

While you're doing all that, pieces and parts of your life are falling away, whether it's a job, whether it's your home, whether it's your transportation. Moving away from where you used to live, friends that disappear.

...There are too many caregivers that are burned out; and not realizing there is light at the end of the tunnel, and better yet, there is light while you are *in* the tunnel..... No one's showing up, you know? No one's showing up to give me that break. No one's showing up to walk a mile in my shoes....

A caregiver may or may not be present, not because they don't want to be, but because they're overwhelmed. Because they're struggling.

Pat expressed the importance of balancing the needs of elders with the needs of the family members who take care of them. She advocated compassion for both groups:

We need to consider our buddies, our people journeying through Alzheimer's. We need to consider those that care for them - and have compassion for them and be getting back into their lives. And we need to start some system where, as you said, we're valuing others. We need to

²⁸ Eg. by Squires et al, 2015.

teach families how to value other family members that have been doing the work.

Carolyn also advocated compassion for both groups, and would like to see more emphasis at the retreats on addressing the challenges for home care partners:

I have too many other obligations in life to become utterly selfless for my Mom... I guess I felt like Memory Bridge wasn't about that. It wasn't about the needs of the caretaker - at least I didn't feel that it was. It was very much about the important work of entering into relationship with people who have dementia in an ego-less way so that they can thrive. And just setting yourself aside - so that you're in a relationship that's not about you; it's about them.

And that is noble and beautiful, and it's what we need to do. But in the course of a day or a week or a year or a lifetime, that needs to be balanced with being on the receiving end.

She also brought up the gendered nature of caregiving, and the imbalanced gender expectations around altruism:

After eighteen years of child-rearing and five years of dementia caregiving, I have a lot of experience with selflessness, and I am aware that it can have a dark side. I know that the essence of Memory Bridge is not about diminishing ourselves in service to the person with dementia; it is about enriching both ourselves and that person through a deep human connection, free of ego and concern about status. But historically, when

women go through life unconcerned about striving - setting our egos aside
for the sake of a higher cause - we pay a price.

At the same time, she appreciated the space, beauty and time to reflect that the retreat gave her, as is evident from her comments in Chapter 3.

As noted earlier, Michael designed his program to give emotional and physical nourishment to dementia partners, and most people – home caregivers included - came away feeling fed. For Pat, Sarah, Maeve and others, the retreat provided a reprieve and a contrast and a sense of being valued. Christiane said, “I felt so helped and looked after” and Sarah was quoted in Chapter 3 as being moved to tears by the gift of the retreat “with no expectation of return.” Meanwhile some of those who were in professional positions came away with increased awareness of the needs and feelings of family care partners because of their visits to Autumn Hills. In Chapter 3 I noted that Magdalena, Julia and Heather described this as a key learning from their buddy visits.

A large number of the people in professional positions – especially those who worked in large medical institutions - discussed the challenges for effective caregiving in these settings as well. They were painfully aware of systemic obstacles to adequate social connections between staff and elders – shortages of staff, money and time. Mary Jo started her own residential care center because of these problems. Debbie noted that the traditional health care system was designed, “for convenience for us as caregivers; and out of ignorance it is task focused not people focused.” She pointed out that a typical staff ratio is three to four aides for *sixty four* patients, and acknowledged,

It’s not humanly possible to keep this many people cared for holistically.

We would be lucky to just do the basics of physical care adequately, let alone

care for their personhood and be in relationship with them. They become just a diagnosis. It doesn't have to be this way... The medical model is not working for this population. It gets staff rushing through their day. It's time for a revolution in traditional healthcare. We have to become about relationship and inclusion. There are far too many people living with dementia who are dying of a failure to thrive because we have disconnected them.

Ryan echoed this, linking the problem with national economics:

(We) here in the United States need to revisit how we staff these facilities. Right now we try to do it in a cost-benefit ratio... It is like two to twenty or something. It is not doable and it is not humane.

And Angela also drew links between staff shortages, economics, and political priorities:

I don't need lots of gadgets, more computers. I need kindhearted people. That's the resource that I need... That comes down to economics. People can be kind and caring. But people have got bills to pay, and kids to feed, and kids to go to college....

It comes back to a culture where the money is not going to go to the end of life issues....We don't put our money where our mouth is, because we say we care about the elderly but we're not willing to fund the caregivers. Or the families who are acting as caregivers; who have had to give up their jobs to take care of someone with dementia.

Trainees who came from other parts of the world than the United States expressed similar problems. Even where dementia care receives financial support from governments, the support is geared towards practical, measurable tasks rather than social connections. Emily described how the United Kingdom's National Health Service focuses on items that can be listed and checked off, to the detriment of aged care:

There's a phrase in the healthcare literature: "hitting the target, but missing the point"... You do what you've been asked to do. Because if you are told to fill something in, or that's what you need to report, then often that can miss the essence of some of these really fundamental principles that often there's not "time" to consider in a health and social care system that's hugely buckling under the weight of demands, lack of resources, etcetera.

Christiane described the flurry of activity that develops when people die at the German institution where she works. The staff are confronted with so many physical, practical challenges that they can lose sight of the person going through the experience. She looks back on her own respite during the Memory Bridge retreat, and wishes that the nurses could be given the same gift:

Every opening of his body coming out, and the nurses have to learn how to deal with all that. And then in the middle is the person who's dying. And then it's very difficult to stay calm and not hurry up; and do it in a right way.

I am very much with Michael's philosophy of feed-the-feeder, because I felt so helped and looked after. To be able to take part in this retreat and slow down and have time to reflect a little bit - where I come from and where I am going to. And I think this is something everybody needs. I'd really like

to find a way to offer something like that for all those running nurses - try to offer a safe place.

The trainees returned to difficult circumstances, but most, like Christiane, came back reinforced in their convictions, emotionally nourished and ready to take a variety of initiatives. Gina also noticed the challenges of bringing Memory Bridge's worldview into care settings, partly because of the way the systems are set up, but also because it is such a different way of thinking:

It is down to resources, to understanding, to so many things. And also there are a lot of people, even in care, that... actually believe "What is the point in connecting because they are going to forget about it?" This couldn't be further from the truth.

But she saw great power in small efforts. She has continued to advocate effectively for people with dementia through the English media, and has also brought publicity to Memory Bridge. Thanks to her outreach, for example, *Devon Live* ran an article about the retreat, in which she expressed some of its messages clearly and powerfully:

The volunteers spent time with "buddies" at the center, and Gina explained how the power of touch and music enabled a liberating connection.

"But there were also times when no words at all were exchanged, and those moments were powerful", said Gina.

"I understand many people in society sense a social awkwardness around dementia generally. In the past I did too so I have a great deal of empathy with that..."

I believe spending as little as 30 minutes of quality time really “being with” a person living with dementia in their reality can be the difference between a life of quality inclusion and social isolation.”

Devon Live, 1st August, 2015

Several others also noted that small efforts could make a relatively big difference to elders with a dementia diagnosis. Jill said that she found it not only less daunting but more effective to think in terms of short increments of time and attention:

It has come to my awareness that there are people in society that are emotionally malnourished. And how many average Americans live on the emotional equivalent of McDonalds, and they can't figure out why they feel stuffed but empty? But ten minutes of meditation, especially day after day, makes a huge difference. Ten minutes of real connected communication, verbal or non-verbal, can make a huge impact. Sometimes we think more is better but sometimes more is more than a person can absorb. Like a thunderstorm, and the rain just runs off.

....Little bits of time here and there, little connections, little things, really can make a difference. Sometimes we think the problems are too big so we don't know where to get started. Or we just think, “Oh, this is just a drop in the bucket”, but - drop, drop, drop..... Dripping water can wear down a mountain. Small, steady, and one focuses on each drop. Let go of the mountain and it is a lot easier to continuing dripping.

Cheryl also points to the power of thinking in terms of particular moments and particular individuals rather than being daunted by the scale of elders' needs:

We all know the statistics. We all know numbers, the plague, the epidemic.

We all know that. What are the barriers that stop us from going and actually visiting people?...

When we listen to other people, no matter what the situation, the single most important thing in that moment is that we give the other person undivided attention. That we take time to be present with them, in that moment, at that time, when now is all we really have. We can't change the past. And we can't predict tomorrow. But we have the ability to make *now* better.

She told me of a horrible incident of elder abuse in an aged care institution that had got into the Australian newspapers after a relative had put a secret camera into the elder's room. She was shocked, but she also could see the systemic pressures that got in the way of human connections in the institution. She noted that both a change in cultural perceptions and a change in the position of care partners were important if things were to change. She saw a need for greater outreach to volunteers:

I'm sure it comes back to that lack of understanding that a person is still a person; a person still has feelings; a person still has emotions. Just because they can't tell you about them...does not make them less of a person...

But, yeah, it's that busy, fast pace, and probably that care worker's side would have been "I had to hurry; I had six other people that needed my

assistance, just to give them their food.” And so maybe he wasn't deliberately harming the father? Maybe it was the pressure of his job that made him do that. But it's just not acceptable.

...To my students I say, “Look, I am using a perfect world of theory here in this classroom. Everything is possible... But once you're out in the workplace, that's reality. And you have to marry up the theory with reality somewhere in the middle. We have to find what they call that “best practice.” Really, we're really up against it, and I think that the only way we can get Memory Bridge to work, or to bridge that gap, is by appealing to more people to volunteer their time.

Several participants suggested another possible approach to dealing with the pressures of the health care system – combining “doing for” with “being with.” When describing her father, Pat said that he could tell intuitively when one of the medical staff acknowledged him as a human being and when he or she didn't. Jill and Jeanene said that being consciously present with elders made the many “doing for” tasks go more easily. Jill told me about a staff member who was skilled at working with a particular elder:

She always tells (her) exactly what she is going to do before she does it... It is because Frederica is totally and completely present and is really patient, and guides her and preps her and treats her with respect. She knows that this patient is particularly modest and so when she gives her a bed bath, she keeps every other part of her covered up... She treats this woman as a sentient, dignified elder, not as a shell of a person who does not know what is happening with them....

When you sit down and spend five, solid, unhurried, incredibly, present, minutes with somebody, what ends up happening is the trust and the vibe that you create, creates someone who is much more trusting. So that when you do give a bath, it is not an ordeal and this person is not fighting you...

And that is one thing that Jeanene taught me - you've got to learn how to talk to people.... trying to point out how this kind of care does not take more time. It actually in the long run, counterintuitive as it may seem, saves both time and energy... I experience that on a daily basis. People come in and they are in a hurry and they are brusque and people resist. But when you come in slowly then people don't resist.

Plans and Projects

Having touched on some of the participants' thoughts on the challenges to caregiving, and how to deal with them, I will now turn to more of their plans for implementing Memory Bridge's ideals. As I wrote earlier in the chapter, most of them came back encouraged in their convictions and emotionally replenished. They expressed their desires to express their convictions in a variety of ways. This next section will be based mainly on their interviews after the trainings rather than a full account of what they did in the ensuing years. I realize that it will provide an incomplete and imbalanced picture - giving only a few snapshots of trainees' intentions and projects soon after they returned home.

Stuart came away determined to convince family members of the importance of visiting their relatives in long-term care:

Up until now, once my guys go into long-term care, I've been very reluctant to go and visit them. Because I find that heartbreaking. And I think what Janet (his buddy) has taught me in that regard is that I should stop feeling sorry for myself and pitying my reaction to their incarceration, for use of a better word. And I should forget about me and think about them more. Just go and put a bright face on, and go and spend some time with them and lift their spirits in the place that they're alone in.

Fortunately for me, I know the families of the men I'm with, and they're in every day. I know they are not dumped or warehoused or whatever; that their partners and their families are going in to see them on a regular basis, whether that is daily or at least two or three times a week.

...If I come visit every bloke I've got, that's ever come through my program, I'll be forever visiting... But what I *can* do for them is teach their families to stay connected with them. I think at the end of the day, that's what Michael wants. Is for that to occur. So, I suppose in a roundabout fashion, I've still got the message.

Sarah considers the learning she took from the Memory Bridge retreat to be a spiritual practice – a way of interacting with all people:

I still wear my bracelet... Just looking at those words, “I am a bridge” - and having people ask me what it means, and having the opportunity to share

what that experience was like - keeps it alive for me and reminds me, that's why I am here. This is my ministry. It is important for me to think that it is my spiritual practice.

It means cultivating that presence with whomever I am with... I think there is a level of presence that needs to be there to make our connection...I try to apply it with everyone, and especially with myself and with this population of elders and more especially, since the retreat, for those with dementia.

For me it has never been just a job. It can't be just for money - there has got to be some higher purpose. I like the word ministry. I am not a minister or anything but this is the population that I am called to be with.

Molly expressed a combination of a change in attitude and some concrete applications for her place of work. She trains student volunteers.

I work in a nursing home and I walk on the floors, a lot of time on the floors looking for the students, and I think I am just much more aware of our residents and what they are experiencing. And if I do have the time I think it is important to take a minute to say "Hi" to someone and see how they are doing....

One of (the students') main roles is to offer support and socialization for the elders so they really do have the time to do stuff like this. So I told them about Memory Bridge and I told them about the experience, and they chose an elder mentor for this whole week ...One day I showed the Naomi

clip and they were really moved by it. But what was even greater was that some of them had already been doing things like that. They had picked up on all the small details in that clip. And (they) could speak to how there are some people that from first glance seem like they might not know what is going on. But when you really engage with them you can see that someone is really there. At that point they had a week left in their internship so they spent that last week to really try to connect with someone that seemed like they did not get that interaction or connection

My plan is for the next group - where they start from the beginning - is to do a mini Memory Bridge. Like what we explored - the questions that we explored. I'll have them do that activity where they look into each other's eyes; and part of our program is they find that Elder buddy.

Susan is the founder and director of an organization called ARTZ Philadelphia, where she engages elders with dementia with the arts. After the retreat she commented on the ways Memory Bridge enriched her teaching, and said that she thought it would continue to do so:

We were using art and art-based experiences, and I was teaching it with a colleague who is herself a minister and a pastoral care giver. I found chunks of what I had experienced in Bloomington entering into my experiences of teaching this class. In the process of working on this new program that I've talked about, I have a feeling there is going to be a lot of reflecting back on how I can model it in certain ways on the wonderful things that Michael introduced to us.

In the last section I noted Gina's extensive outreach with the media on behalf of people with dementia. In 2016, she inspired and created a Dementia Friendly General Practitioner²⁹ resource guide, which was shared across Devon - the county in England where she lives. As this report goes to press I also heard that Gina will be receiving a British Empire Medal (B.E.M.) for her voluntary services to dementia in Devon.

Ryan, as I noted in Chapter Three, incorporated Michael's ideas about the social "dis-ease" around dementia into his lectures at the wellness institution where he works. When I talked to him after the retreat, he had also been living out this learning through his own interactions with elders:

One of the commitments that I made after all of this was to spend time each week in our memory care community; and I have done that. I was just there yesterday actually. And it has become a really meaningful opportunity for me. Each time I step in those doors of that community - to try and let go of the expectations, whatever they are.

Heather described a dramatic shift after the retreat, in both her perceptions and her plans. She planned to combine the insights and empathy she had got from Memory Bridge with some workshops in Naomi Feil's Validation Method. Before attending the retreat she had begun working on a large grant for her rural area of Wyoming. On her return she changed the grant application completely:

Coming home I would say I became a different person. The way I look at dementia shifted completely. I began to see what I imagine to be through the eyes of people that have dementia...

²⁹ In Britain "General Practitioner" is the term for a medical doctor.

What I realized is we needed more information from those with dementia in order to do better care. And the only way to do that was to get really close to them; to get comfortable in the Valley of Awkward...So basically, I rewrote my part of the grant. I was keenly aware that there was no way to explain my experience without actually helping people have their own experience, so what I developed as part of my part of the grant was a way to bring Validation to the city.

Considerations for the Future: Adaptations or Changes Suggested by the Trainees

In a program where listening is so central, it makes sense for the curriculum to change over the years in response to participants' input. In two of the sections in Chapter Three, I noted Michael adapting to suggestions - over timing in the circle and over introductions at Autumn Hills. In the course of describing each element of the curriculum I have included their other comments on what might be changed, and I will briefly list these here. Since people had very different perceptions of the same activities, I use the word "considerations" in place of "recommendations." They reflect trainees' diverse experiences and could be born in mind for future Memory Bridge retreats.

- One suggestion was that meditation be made optional, and some substitute activity be offered for those with incompatible religious beliefs.
- Several people suggested more accessible language in the formal talks, and/or a greater proportion of stories, shared experiences, or activities initiated by the group.

- Introductions at a memory care unit could be explicitly framed around the elders as mentors and guides. Entry could be staggered and a simple rationale for the visits could be prepared ahead of time.
- The camera had an inhibiting effect on some of the trainees in 2016, when many activities and circles were filmed. I did not ask questions about this, but six people told me that it made them uncomfortable. Obviously there were tough choices to make here; some of the footage was later used in the movie, *Love is Listening*. However it could also detract from the intimacy and safety that Memory Bridge works so hard to cultivate.³⁰ (People expressed a lot of appreciation for the camera crews, however, including for Peggy, who had attended Memory Bridge herself, and who has volunteered her time for several years, and including Ted Kay and his team. Each of these people became a valued extension of the group community.)
- There could be more explicit discussion of the needs of family caregivers, who often feel devalued and isolated along with the people they care for.

It is important to note that only a few people made suggestions for changes. They should therefore be regarded as possible adaptations to keep in mind. Most people, for example, valued the meditations and the formal talks. And most people valued the retreats as a whole. This should be clear from the earlier parts of this chapter.

³⁰ Bernstein, 2014. Research on being visually recorded suggests that it makes people more compliant and less creative.

Overviews and Summaries

I will conclude this chapter with a few of the summarizing comments on the Memory Bridge training experience. The vast majority of these comments were positive, and it was clear that while dementia care was the central focus, people took away lessons that went beyond it. Emily, for example, said,

I genuinely put “life-changing” on my evaluation form... I really felt as if it gave me insight and perspective on some of the really fundamental things that make us human and also makes me *me*.

And Susan said,

I thought I was going to a retreat and a training about the work that I do with people with dementia. And it became clear that what I had actually taken away with me was certainly that, but much, much bigger, as well.

Magdalena and Stuart were surprised by what they came away with. Magdalena said that her two biggest takeaways were first, the empathy she developed for family care partners as a result of her buddy visits, and second, the inspiration she took from the varied people she met in the group. She also came to re-conceive the way she thought about dementia, (I will come back to this in the next chapter), and she had improved her listening skills, with self and others. She said,

If you go back to what my expectations may have been, they were not fulfilled - as far as what I *thought* was going to come to me. But it was something different. It was very different things that I arrived at.

Stuart expressed his surprise about the retreat in characteristically vivid terms:

I've gone to the supermarket for a packet of chips, and I've come back with a hamburger. And I don't know how I did it.

Maeve also expressed surprise, in the sense that the Memory Bridge retreat stood out as an unexpected gift in her life. She thought it would be a gift that lasted for a long time:

It was such a privilege to be there in that environment... I'd say that it's was the highlight of my life. Something I totally did not expect would ever happen to me... Professional and personal. Both.

... It's just been such a positive, wonderful adventure - something I'm so glad I did, and had the opportunity to do. I'll remember it fondly into the future. Very affirming. Very inspiring. It's like a little pot of gold I can keep coming back to and extract nuggets from. It's given me such a rich resource for the future.

A few of the trainees expressed the benefits they had received in terms of feelings. These were also quite vividly expressed. Pat said, "It put a smile in my heart..." Marigrace felt that her whole self had been accepted in the community, and saw this as increasing her ability to give to others:

It is helpful to have that feeling - to have that body memory and to be able to feel what it's like to bring more parts of myself into the discussion.... (It's a kind of, storehouse, or warehouse, of love to move forward with.

Marigrace's words, along with a lot of the other comments in this section, highlight the non-cognitive aspects of learning. This is one of the topics I will go on to discuss in the final chapter of this report.

CHAPTER 5. “PERFECT TEACHERS”: SOME BROADER IMPLICATIONS OF THE MEMORY BRIDGE RETREATS

Listening happens independently of words, or the meaning of the words, and even if there are no words, there is listening to quietness. People with dementia sometimes take us on spontaneous journeys in a different time or space; they are so open and vulnerable. They are perfect teachers.

Christiane, Facebook post, 2016

I told my husband, “If you want to learn about love, go into a nursing home and work with people with dementia.”

Maeve, 2015

Memory Bridge’s core message is that cognitively frail elders have something to teach the rest of us. It is a message that turns on their heads many current ideas about medical care, about pedagogy and about dementia. There is considerable overlap among these three areas but in this last chapter I will take each separately, because all of them have implications for policy and practice. Finally I will conclude with an impression of what is unique about the training retreats. They are characterized by a kind of upside-down normativity, which has cultural, as well as practical, implications.

Broader Implications for Care

The most striking difference between Memory Bridge's approach to dementia care and the mainstream medical approach, (as it is actually *practiced* in many institutions), is that the organization's focus is on connecting with elders rather than on handling the tasks involved in their care. It prioritizes being over doing. While the tasks cannot be ignored or wished away, what matters most for elders, (and for most people), is the experience of being included in a human community. If connection and community are the goals, the means to these goals is attention – broadly categorized by Michael as “listening” but also encompassing other forms of active interest. Further, hierarchy gets in the way of real community, so this attention should be reciprocal, and respectful of elders.

This, in turn, assumes that there is value in human qualities other than cognitive competence, verbal expression, productivity and/or the ability to follow social norms of behavior. Cognitively frail elders are valuable. Care and care partners are valuable. Affection, communication and attention are worth teaching and worth learning. These are the essential building blocks of human wellbeing – and in Michael's worldview they are more valuable than instrumental intelligence.

Maggie noted, in one of the circles, that – besides being a good in itself - listening invites lucidity. Several other participants said in their interviews that having other people listen to them reinforced their own listening and expression. Being heard in the circles or in informal settings freed them up to attend to others, and enabled them to speak fully and authentically. They also recounted quite moving examples of elders becoming lucid and engaged simply by receiving attention. Debbie's, Sarah's and Magdalena's buddies, for

example, were significantly more communicative by the end of the retreat. And Jill described a parting scene where her buddy had put this idea into words:

We put our arms around each other, and he said, "It's so nice to have someone who listens. It makes me feel better, it makes me think better".

Natalie described a similar incident, from before the retreat. Just the fact that she was listening with interest helped a resident to think and speak clearly:

I was talking to a lady with dementia... All of a sudden she looked at me and she said, "We've been talking for a long time. And I haven't lost my words!" She was so excited that she had been able to converse for that long. And I thought to myself, "I bet there hasn't been anyone who's actually sat down and given her the time to have that conversation."

While they point the way to effective dementia care, these examples also illustrate the need to strike a balance between attention to others and attention for oneself, (since receiving attention enables people to be expressive.) At the beginning of this report I discussed a few other dementia care training programs that advocate attention to elders, respectful relationships with them and an attempt to look at the world from their point of view. One of Memory Bridge's additional contributions is that it creates emotionally sustaining experiences for care partners. It offers spaces where care partners can cultivate community among themselves and feel heard and valued. This gives trainees - to use Marigrace's phrase again - an emotional "storehouse" which can then be carried forward to others.

Broader Implications for Pedagogy

A second, practical area where the Memory Bridge training model could be used is in education. The idea that there is more than one way of learning is not new. In 1983, Howard Gardner argued that there are multiple “intelligences”. I also mentioned Expeditionary Learning in Chapter Three, as one of Greg’s areas of expertise. And Naomi Feil’s Validation Therapy emphasizes the heart. While there are exceptions in dementia care, (more are noted above in the Introduction), most mainstream medical education remains geared to logical, practical thinking – “doing for” rather than “being with.” Memory Bridge’s varied curriculum has much to offer as an example, since it engages human qualities beyond the intellect. The idea of learning through the visceral experience of what it is like to belong in a community is unusual. Acknowledging and working with shame is also unusual. The training makes use of a number of non-verbal, non-cognitive modalities to enhance community. Emily noted that it had given her an enhanced appreciation for non-verbal means of communication – “a whole world out there”. She remembered,

Some really wonderful non-verbal moments where we were connecting but not speaking... whether that was listening, whether that was tactility, whether that was through eye contact, whether it was through dance or through movement or through play.

... I learned that there’s a whole world out there, in terms of connecting and communicating, that doesn’t require spoken or written language.

Michael considers the main learning in the retreats to come from the elders, *because* they are not trapped by intellect or language or personas. Magdalena said that she

benefitted from un-learning with her buddy at Autumn Hills – she benefitted from letting go of the cognitive side of her mind:

It almost felt as if I needed to forget what I knew about – to learn how to make connections, to let myself in, really, to the moment. Which then enabled me to make a new connection.

Besides going beyond the cognitive, the retreats take a bottom-up approach to pedagogy. As participants pointed out, they learned a lot through coming together with a group of other emotionally astute care partners in a safe environment. Non-hierarchical learning is central to Memory Bridge's philosophy. In the training retreats, ideally, the trainees learn both from elders and from one another. This makes sense in a program which values other qualities besides cognition. It also reflects Michael's belief that hierarchies undermine community. Marigrace, who works in a hospital setting, took this model to heart. She came away from the training with a new determination to acknowledge and include the personal experiences of caregivers in her own teaching.

I am starting an advisory group ...and so I have been thinking about how I am going to set the tone. I was thinking about inviting people to recognize their backgrounds or degrees – (and that) drawing upon anything is valid... If you are a personal caregiver and don't feel like you have all that expertise, that your experience is valid and they *do* have things to share. That's how I want to set the tone.

There is a paradox in the fact that the flow of learning from elders to trainees was encouraged through Michael's particular gifts. He spoke with charisma and passion, and he was a skilled storyteller. Importantly he also modeled listening to and learning from others

- being open, for example, to their suggestions about changing the way participants approached elders at Autumn Hills. I will quote Pat and Marigrace on how Michael designed and implemented the program because their words point to both sets of skills - as a listener/facilitator and as a speaker. Here is Pat:

It was his stories, it was his presence, it was his willingness to be open and vulnerable, it was his willingness to balance in harmony all sides of who he is, both as a researcher and as someone that has a heart. It was everything. It was, when he took in the moment to realize, "You know what? We're all tired. Let's shift the schedule just a little bit." And we'll still get a beautiful collage of experience out of this at the end. It wasn't what traditionally happens in training workshops...he allowed it to organically unfold.

Which is what you want in a vision, which is what you want in something that's a catalyst for change. You want it to organically unfold, and not be forced, not be seized, not be oppressed, not be manipulated. He organically allowed who he was to unfold, and in that way we were allowed to organically unfold into who we were, as the essence of what Memory Bridge stands for. That we could then take that back with us in our heart. And apply it in our lives, help others apply it in their lives, whether that's in a professional manner, a personal manner, or whatever.

And here is Marigrace:

He scripted it in a way that there was so much freedom... Michael is investing himself and there's relationship building, passion and

commitment. And what happens from here out is based on who the people are... and how things play out.

Broader Implications for Perceptions of Dementia

Memory Bridge's most radical teaching - one that underlies the other two areas - is in its perception of dementia itself. Michael, along with many of the participants, emphasizes the gifts of dementia. Susan founded her ARTZ Philadelphia organization on a similar idea - that dementia brings benefits rather than (only) deficits. Brenda, Pat and others refer to the process of dementia as a "journey", which provides insights. Along its path, as Christiane pointed out in the opening quote for this chapter, time becomes more fluid, words and judgments are released, and individual identities are blurred.

Through her activities with ARTZ Philadelphia, Susan is reminded frequently of what dementia can offer:

In my daily work, I see people who have dementia - even way into the illness - who are becoming more creative, and are laughing more. And are discovering parts of themselves that were literally filtered off before the disease came into the picture....

This recognition was always an underlying assumption in her organization, and she had plans for the elders to offer their gifts to others:

Im in the midst of working on a program in which our constituents with dementia and their care partners are actually going to be mentoring medical students starting this fall.

Pat noted that care partners' connections with cognitively frail elders challenged them to get in touch with non-verbal, freer ways of being. She said,

If you can get yourself very present in their presence, then their presence will recognize it and they will become present to you. And from that plane, you all can communicate - it may just be with your eyes, with a smile, a touch, with a hug, with a tapping of a foot, or a memory of a song. It has absolutely nothing to do with worrying about putting sentences together...

None of that. Just. Be. Present.

Brenda expressed reverence for elders' detachment, seeing qualities in them that she wanted to cultivate in herself:

Yes, it is such a difficult journey, but it is not a death sentence, it is not a prison and it is not all of these awful things. It can be a magical, spiritual thing. And I am not a spiritual person but I really value that our elders who are on a journey - they can be so fluid, and so above the world that I obsess about all the time.

Conclusion: Upside-down Normativity at the Memory Bridge Retreats

The Memory Bridge trainings in 2015 and 2016 promoted an ethic of unconditional acceptance among the participants. Michael reminded everyone that there was no supervisor sitting on their shoulders, judging them. I noticed in these groups, however, especially in the first two days of each retreat, that some participants judged themselves as if from the perspectives of the elders. Reactions from the buddies became,

for that space of time, the measure of identity - occasionally prompting a sense of having failed. This was a very unusual situation, one where people with dementia - people so often looked down on or ignored - were in the roles of judges. A couple of days into the retreats this anxiety seemed to ease, and people expressed appreciation for the elders and for one another.

Among the general public, dementia inspires fear. Its differences are seen as upside-down - as problems to be resolved. The Memory Bridge trainings highlighted the upside-down qualities of “normal” thinking instead. They took the experience of cognitively frail elders as central, and saw the world and the rest of us from *their* position, rather than vice versa. In one of the last circles in 2016, Michael reiterated the point he had made in a formal presentation, saying,

Love is not normal. It is more than normal. Norms are huge breaks and boundaries in our relationships. Dementia is a chance to break out of the norms we’ve internalized.

Mainstream norms, then, not dementia, are the problems to be solved.

In 2015, Marigrace told the group about her buddy, Maud, who had talked about how “normal” people were afraid of the elders with dementia. Maud’s insights and humor inspired a lot of admiration among the group. She became a kind of hero. When Brenda met Maud for the first time, she said,

I was so excited. I was like, “Oh my goodness!” I was in for a treat. She was like a rock star in our group, and when we got to meet her we were like,

“Maud, yes!” And, what if, we created that sort of positivity and celebratory messaging all the time?

This vision is profoundly counter-cultural. Although some politicians pay lip service to elders, to aged care and to care partners, and although many professionals have a sincere desire to implement inclusive and respectful dementia care, it is economically and emotionally under-supported. The things that are rewarded financially in a society tell us a lot about what it truly values - “productivity” (where this is interpreted as producing what people will pay for), certain kinds of physical appearance, certain forms of intelligence, confidence and competence in navigating a world designed for the able bodied. Including and supporting people with dementia and their care partners requires a shift in values. Memory Bridge works toward that goal - spreading and reinforcing its message through the people who attend the trainings. Maud and others are perfect teachers because to see them as mentors is to turn the reference points in our culture upside down. They teach us to let go of judgments, they teach us to love, they teach us to be willing to be forgotten.

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