

**NOMINATION FORM
COMMISSION ON HIGHER EDUCATION SERVICE LEARNING COMPETITION**

Institution

The College of Charleston

Title of Project

Healing Narratives: Understanding Illness through Storytelling

Project Director

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Establishment Date of Project

Fall 2009 (under Kathleen Rogers) and Fall 2011 (collaboration)

Unit That Administers Project

First-Year Experience (FYE) and Honors Program

Total Number of Students Involved

135

- 1. For purposes of this competition, the Commission on Higher Education defines service learning as college student learning at any level and in any situation that is *linked* in a direct, hands-on fashion to the resolution of a problem or concern in a target community outside the institution *and is related* to a college course with some type of reflection activity. How does your project meet the parameters of this definition?**

In our courses (both at the first year and Honors levels), students begin with Rita Charon's theory that "Telling stories, listening to them, being moved by them to act are recognized to be at the heart of many of our efforts to find, make, and honor meaning in our lives and the lives of others" (Rita Charon, *Narrative Medicine*, 11). In the First-Year Experience learning community (two linked academic courses supported by a synthesis seminar led by a peer facilitator), the English component consists of reading and discussing printed stories of illness. In the Psychology course, students learn about the psychological issues behind illness and aging; they also learn clinical interviewing skills and reflect on their interviews in relation to the theories presented. It is important that the students have an academic foundation and the appropriate skills training before they apply their knowledge in the community. In the Honors section, we integrated the same two classes but required a higher degree of critical analysis of research along with the practical application of knowledge to the community.

Students work in pairs and choose a community organization that has already agreed to participate and expressed a need for a volunteer to meet with an identified individual who would benefit from telling his or her life story. The goal is that by telling one's story, "healing" may occur. For some of these individuals, this may be their only visitor that week in addition to the health care providers from the community organization. We have worked with a variety of hospice and senior care establishments, including the Hospice of Charleston (formerly Odyssey Hospice), Agape Hospice, Canterbury House, Sandpiper Rehabilitation, Heartland Hospice, Bishop Gadsden Assisted Living, and Somerby Senior Living. We also recently began to work with the College of Charleston's REACH program in order to hear stories of intellectual disability. All of these stories reflect the social aspects of illness and disability, whether they be race, class, gender, religion, or community. At the end of the semester, students write up a "narrative" of their person—this can be a scrapbook, a conventional story, a video, a diary, or whatever they think is fitting, and give that person's family, and their organization, a copy. During the semester, the students keep an online confidential journal reflecting on their service learning experiences. In a final paper, students analyze the narrative produced, evaluating its efficacy as a (psychologically) "healing" narrative and incorporating the research and analysis of the psychological components prevalent in their person's story.

Once they have completed their final projects, the students present their person's story, along with their literary connections and psychological research, in a 10-15 minute presentation. We invite all of our community and university partners to this event. The presentations are a powerful ending to the course. Students frequently report plans to continue with civic engagement and the community organizations report plans to continue working with our students. Both view the collaboration as mutually rewarding for the population sharing their stories and the students hearing and processing the stories.

2. Specifically, which segments of the college/university community does your project involve?

Our classes primarily involve first-year students where we believe the opportunity to develop the habits of community engagement is prime. We have included other special student populations from the Honors College and the REACH program. The Honors College is designed to offer the liberal arts tradition through personal attention and support with students who are viewed as having impressive academic credentials. The faculty and staff are charged to challenge these students to view the world from multiple perspectives. Students are known to value academic scholarship, participate in leadership positions, and have a commitment to on-going service and community partnership. Our Honors students were no different in their desire to learn, evaluate and discuss Healing Narratives.

The REACH (Realizing Educational and Career Hopes) program is a four-year certificate program aimed at students with mild intellectual and/or developmental disabilities (since we also interview REACH students, we write more about this demographic below). They attend our classes and are grouped with two traditional students in order to go into the community and conduct interviews. Many of these students are interested in careers involving education, communication, or health care; they choose to take this class, write modified papers, take modified exams, and receive assistance from tutors, graduate mentors, and the professors. This has proven to be a very fruitful and exciting collaboration, and the participation of these students has only heightened the impact of this service learning course. One of our REACH students, a young woman with Down Syndrome, even interviewed then-president George Benson about his experience with Lyme disease.

3. How many students (specify degree levels to the extent possible) does the project affect?

Directly, the project has impacted about one hundred and thirty five: 120 traditional students, 12 Honors students, and 3 students in the REACH program. In addition, we have included one REACH student to tell his story, and we hosted a panel about Post Traumatic Stress Disorder (PTSD) that drew 120 audience members, most of whom were students (including student veterans).

4. Describe the target community or communities your project serves.

We believe our course fulfills the definition of service learning through community engagement; instead of serving one community, our students are also served, creating a mutually beneficial relationship.

Our target community organizations represent a wide variety of individuals. Canterbury House is available to individuals over the age of 62 under income restrictions. These individuals are mostly lower-middle class and vary in terms of country of origin, ethnicity, race, class, and religion. Somerby and Bishop Gadsden are senior living facilities which serve members of a higher socioeconomic class.

Agape Hospice, the Hospice of Charleston, and Heartland Hospice also serve a wide range of individuals; some live in their homes in various parts of Charleston while others live in nursing homes.

The REACH students are also diverse; they come from a variety of US States, present with a range of disabilities, and vary also in race, ethnicity, and SES. These students have a significant limitation in intellectual functioning and adaptive behavior which begins before the age of 18. The focus of the REACH program is to allow students to earn a certificate in an area of concentration on the college-level. The initial goal is to learn to navigate the college campus. Students in this program are also working toward building their adaptive functioning by learning activities of daily living, such as doing laundry, cooking, managing money, and using cell phones. Many of our traditional students are unaware or under-aware of this population, so the interview serves to inform not only the interviewers but also the entire class.

Preparation for this service learning course begins well before the start of class. Community organizations which serve senior citizens within a 25 miles radius of C of C were approached or approached us concerning this course. When we agree that there will be a mutually beneficial service and the organizations agree to participate, a representative of the organization is identified as the "volunteer contact." We arrange for all the volunteer contacts to come to the college and present their organization to the students. Students rank order their preferences, are matched with an organization, and then a Memorandum of Understanding is signed by all parties.

5. Describe your project's effectiveness in helping to solve the problems or concerns in the target community.

Loneliness is a chronic problem facing the elderly. As people live longer, more and more spend their time in a room or a facility, often alone. Not only do they not connect with their community, but they often have little chance to share their stories: stories that reflect powerfully upon the financial, personal, and cultural issues affecting healthcare today. By sharing these stories with college students, elders not only re-connect with their community, but they also have a chance to introduce new students to Charleston and, often, to South Carolina. At the end of the course, the community partners, the storytellers, and sometimes the caretakers are presented with a printed version of their own, unique story. One student group decided to conduct a video interview; after the interviewee passed away, they made it into a memorial video and gave copies to the family. The families appreciate these personal touches, and our students gain different perspectives about illness, life, and the new community they have joined.

According to Dana Madanski, former director of volunteer services at Odyssey Hospice, Charleston, "It appears that hospice patients feel empowered to share their stories with the younger generation. Patients are often identified by their general illness, not their personal health story, and through the use of healing narratives, a patient becomes a person." She goes on to write that "Partnering with the Healing Narratives course at the College of Charleston reignites our employees' passion for caring for those in this critical time of life. We may lose sight of the personal stories and personalities of the people we interact with on a daily basis. This partnership helps us not only see a patient and an illness, but a person and a journey."

REACH students and alumni have a different relationship with the College; while they take integrated college classes, they often do not want to tell their story and be identified by- marked by- their disability. Once they tell their stories, however, they come in contact with their accomplishments, not only focus on their challenges. They see their ability to overcome and

proceed through college similar to their peers. This class allows them the opportunity to do so, and it allows for our students to learn about this groundbreaking program. By learning the personal story of a student their age with an intellectual disability, our students start to see that, rather than being ignored, disability, like illness, should be considered as part of, definitely not all of, a person's story.

6. Describe the degree to which your project enhances student learning while providing specific examples of the service learning activities the college students engage in. Also explain how the service learning activities reinforce or apply what the students learn in the classroom.

Our materials in both English and Psychology directly complement the students' service learning experience. In English, we begin by reading Lauren Kessler's *Finding Life in the Land of Alzheimer's*, about an Alzheimer's facility very similar to many of the nursing homes our students visit. We think about how Alzheimer's has been characterized in our media, we think about how Kessler depicts her patients as unique, singular individuals, and we learn about Alzheimer's and the parts and functions of the brain in Psychology. While not all of our students work with a person who has Alzheimer's (or a caretaker), many do end up dealing with the issues of aging and dementia that the book and the psychology unit cover.

Since there is evidence-based research pointing to the comorbidity of depression and chronic illness with the aging, we read a web comic, Allie Brosch's *Hyperbole and a Half*, in order to better understand the issues that come with this illness (and mental illness in general). Many students are better able to understand or empathize with the psychological states of the people they interview after having read this and reflecting on it during their Psychology class discussions on depression.

This past year, we have also been hearing stories of intellectual disability, so students read Temple Grandin's *Emergence* in English and discuss the learning process in psychology. Here, Grandin's depiction of her own autism became very relevant when one of our student groups interviewed a young man with the same "disability" (he preferred to call it his "uniqueness").

Because this is not a class solely about aging, we also read Lucy Grealy's *Autobiography of a Face*, about the experience of surviving the physical and psychological effects of jaw cancer at the age of 9. In psychology, students learn about child development and the impact illness or hospitalization has on the stages of development, attachment to caregivers, and formation of relationships. Hopefully, in the future, we can work with more child-centered facilities or non-profit organizations.

We also read *The Good Soldiers* by David Finkel to better understand the stories and experiences of veterans suffering from or exposed to Post-Traumatic Stress Disorder. *The Good Soldiers* was the 2014-15 campus common reading selection, so most first-year students were familiar with the book. Students learned a different perspective from same-age peers in the book, and we supplemented it with a panel involving psychologists, a psychiatrist, a community organizer, and student veterans. In this way, students were able to connect PTSD not only potentially with their community contact, but also with community members, medical professionals, and students much like themselves.

7. Is there academic credit associated with the project (not necessary for submission)? If so, please explain the particulars.

Yes. This is part of our FYE (First-Year Experience) program, designed to integrate new students into the academic and cultural community of the College. A learning community (two linked courses) is one option to satisfy the FYE requirement. Students earn 3 credits for each class (6 total) and attend a one-hour per week synthesis seminar led by a peer facilitator who has previously taken the class. In the Honors section, students earned 3 “interdisciplinary” credits.

8. If funding is required, how is the project funded and what is the approximate annual budget for the project?

First year students are not permitted to have cars on campus so transportation to community partner organizations proved challenging. During the first three years of the project, students tried to ride the CARTA bus, but the routes did not reach all of the locations. Currently the First Year Experience program provides \$300 to offset transportation expenses related to the program. All students can now either ride the bus or take a cab to reach partner facilities and private homes to conduct their interviews.

9. Add any other comments you may have about your project.

Kathleen Béres Rogers has written a book chapter about this project, forthcoming in the Modern Language Association’s volume, *Service Learning in Literary Studies*. The MLA is the most prestigious organization in the field of literary studies, and inclusion is an honor not only for us, but for the College (the article mentions the College and Charleston at large). The chapter argues that in this class, the service learning component helped students draw connections between “real life” and the literature they read. Over and over again, students referred to the memoirs we read as they wrote journal entries about their service learning experiences and participated in class discussions. Conversely, they discussed their community members’ experiences as they attempted to make sense of the memoirs. Specifically, students a) used literary analysis, in particular an understanding of genre, to analyze and better understand community members’ illness stories; b) gained a better understanding of diversity, including issues of gender, class, race, socioeconomic status, physical disability, and, of course, age; and c) became active agents in their new community, understanding more about the politics of social justice.

Silva Youssef Hanna has also written a research article (forthcoming) that assesses the direct impact of this service learning course on students enrolled. The interviewing techniques the students learned supported their ability to make connections with the interviewees but, Hanna hypothesizes that these skills can be transferred to building relationships with new individuals on the college campus and in the wider community. After this course, they learn not only how to interview the individual, but also how to actively listen to and empathize with someone else’s story. Here they build a better understanding and respect for similarities and differences between themselves and others. This is the foundation of building any relationship.

If our first year students can transfer this knowledge from their service learning experience, then the relationships formed in college will support their retention at the college.

Supplemental Material attached includes two examples of “healing narratives” produced by students enrolled in the course.

APPENDIX

Sample Narrative #1

This narrative was written by students in our First-Year Experience section. These students were paired with a Polish immigrant who had lived through some fascinating historical events. Because the interviewee consistently mentioned his favorite professor, the students decided to write the narrative as a series of letters to him. Here, they deal with the psychological ramifications of being a caretaker to someone with Alzheimer's Disease; in their final paper, they included research about this as well as parallels with Lauren Kessler's Finding Life in the Land of Alzheimer's, Will Schwalbe's End of Your Life Book Club, and Rita Charon's Narrative Medicine.

August 18, 1933

Dear Professor Wilk,

I thoroughly enjoyed your visit, as I do each summer. I am quite thankful for your painting lessons I received. The sun glistened through the mountains and hit the serene river, reflecting the lively trees as they swayed back and forth through the wind, creating a perfect picture. This I very much enjoyed. Since your lesson, I have been practicing everything you taught me. I felt extremely pleased when you told me I could go to school to become an artist. Father did not find this amusing. He tells me once I become thirteen, I must go to technical school to prepare for college. I will keep in touch!

George

September 19, 1935

Dear Wilk,

On my way to school this morning, I came across the most magnificent girl I have ever seen. With lush brown hair that blew ever so slightly in the wind, immaculate brown eyes that sucked you in, and glowing skin, she was breath taking. I can't imagine anyone more beautiful. You will never guess what I did! I told her exactly what I was thinking- how beautiful she was. She looked amused by it, so I asked her to be my girlfriend, and she said yes! I already feel like the luckiest guy. I can tell you right now, I am going to marry her. Once you see her next summer, you will see it too.

George

July 8, 1937

Dear Wilk,

Yesterday turned out to be quite an adventure. It began as a normal day of work, with me taking a group of people on a tour guide through the Pieniny Mountains. The sun was shining bright and the river was as calm as ever; a perfect day. The tourists often love the scenic tour through the mountains, but it proves to be a challenging hike for some as the tours usually take about five hours. After about three, the sunlight began to slowly dissipate and a fog started to roll in. I initially thought nothing of it and continued the tour since we were close to the peak. Almost immediately we were surrounded by an immensely deep fog that was nearly impossible to see through. With edges providing sudden drops all around the mountain, it was extremely dangerous to even step forward. One member of the group thought it clever to drop a large rock off of one of the edges to determine how far the drop was, just in case we could slide down. After he dropped the rock, several seconds passed and we never heard the landing. We clearly would not be sliding down today. Since the fog did not seem as though it were going to lift any time soon, I decided it best to camp out for the remainder of the night and make a better effort in the morning, something the group was

not too thrilled about. As morning came, the fog was gone and I quickly went to the edge to view the drop. It seemed to be a mere 6 feet! Laughing about this mistake, we began hiking back down the mountain. Even though the tourists were not excited at the time of confusion, they seemed to be joking with one another as we neared closer to the bottom. My coworkers said that my story will be told for years as new guides come and go. I'm not sure yet if this is a good thing or a bad thing. What do you think about it?

George

September 20, 1939

Dear Wilk,

The seriousness of the war is apparent in Poland. Everywhere you turn, there is either a German or Russian soldier walking down the street. Father has already been moved from Border Patrol to Siberia to fight in the Polish Army. Many Germans are slowly beginning to occupy Krosclenka. Mother is very worried about what they will do. Several men are being drafted to fight, including myself. I will be joining the English Army as a heavy equipment driver. Things seem to be happening all too fast. Halina is frightened for my well-being, as I am for hers. We do not want to separate, but I fear we must have to for the time being. I must leave for England in a few days, and do not know what lies before me. The worst part of this war is the mystery of the unknown. No one knows what is going to happen or what will become of them. We quickly realized that we will quite possibly be living day to day without knowing if we will even be alive for the next. It seems as though the safest thing to do is join the war. I pray to God that I am right.

George

November 12, 1939

Dear Wilk,

I just received an unexpected letter from Mother. My sister left a week ago on a train to the city to continue going to college. On the way to the city, the Germans bombed the train, leaving no survivors. It pains me to remain in England as Mother is suffering back home. However, I can not leave. We are getting ready to deploy to Germany and get a front row seat to the war. I do not know how I am going to continue fighting when my sister has just been killed. It seems I have no choice.

George

March 15, 1940

Dear Wilk,

I am currently sitting in my barrack at a German labor camp in Munich. I was arrested and sent here as a prisoner after returning home for mother after my sister's death. I was granted two days of leave by my officer to return home and console mother through this time of morning. He made it clear that I was to return back before the deployment. However, I never did make it back. When returning to Poland, it was clear the Germans had completely taken over. I was almost immediately arrested and sent on a train to Munich with many others. Here, they have us work in a BMW factory making the engines for their planes. We work ten hour shifts in the factory, something I was told that was more of a "gift" from the Germans, as they make most camps work several more. Life in the barracks is harsh, to say the least. Each person is given one blanket, one set of clothes, wood with straw on it to sleep, one dish and one spoon. For breakfast, we are given one slice of bread and a cup of "coffee" that is made from coal. For lunch, the Germans give us their hysterical version of a soup, comprising of a piece of beef in water. There is no dinner. I have been

stealing tools from the factory and selling them to German farmers that are next to the camp in exchange for food. I'm afraid the German soldiers are on to me. They have been paying closer attention to me lately and I am not sure what they will do if I am caught. I see only one solution; don't get caught. I can picture you rolling your eyes at me, being the troublemaker I always have been.

George

June 2, 1942

Dear Wilk,

After realizing how close I was to getting in trouble with the Germans, an underground society helped me escape to Vienna. They gave me civilian clothes to change into, as well as a train ticket to Warsaw. Being that I speak fluent German, I didn't think it would be too difficult to get by them. I was told that the train would be safe for me because it would not be stopping. This was not the case. The train was stopped by German soldiers at the German-Polish border to check for proper papers. Since I had no papers, I would likely be arrested and sent back to Germany as a prisoner. Trying to think fast, I noticed that the person that would usually work on the train while it is stopped is not present. I quickly changed back into my labor clothes, snuck off of the train and grabbed the tools on the ground to pretend I was checking the wheels on the train. A few Germans walked by talking to me with large dogs sniffing the train. I spoke to them with the best German I had to offer, which seemed good enough. Soon, the soldiers were leaving with those who did not have any papers. I snuck back onto the train and changed back into my civilian clothes. While sitting in my cabin, an older woman and her daughter joined me. While trying to look normal, the older woman bluntly asked me where I was escaping from. She then proceeded to say my clothes were terribly wrinkled as if they were stuffed in a bag for a while and passed along. I guessed this explanation was likely because of the stunned look on my face. For the remainder of the ride, I gave them my story and explained I did not know where I would go in Warsaw, because I knew no one there. They offered to let me stay with them in the extra room of their house, something I was grateful for, for nearly two years. However, the Germans came to Warsaw soon enough and arrested everyone on our block. Everyone was sent to different camps throughout Germany. I was taken to another labor camp in Magdeburg, where I am now working in their musical group for entertainment. This seems as though it will be better than working in the factory. I sure hope it is.

George

February 17, 1943

Dear Wilk,

The guys in the musical group are really good guys. Everyone plays something different, and I seem to be the most unusual, with having the musical saw. I quickly realized that this group is merely a joke to the Germans, using it as a false identifier to make outsiders believe those in the camps are being treated well. They make us play for their own enjoyment, as well as for Germans in other camps. Recently, they had us walk seven miles to another labor camp that grows and makes food for the German soldiers. Upon entering the camp, I recognized a face that was all too familiar. It was Halina! After four years of not knowing whether she was alive or not, she is now seven miles from me! We reconnected rather quickly and she assured me they are being treated well. After our performance we were to be immediately sent back to our camp. Before leaving, I promised Halina I would come see her any chance I would get. I plan to keep that promise.

George

October 21, 1944

Dear Wilk,

I have come up with a system of reaching Halina that has been somewhat successful. I have been sneaking out of my barracks on Saturday mornings and entering her's by paying the guards with tobacco. It was crucial for me to return to my barracks before nightfall, otherwise the guards at my barracks would notice I was gone. I was caught one time and the guards continued to watch me thoroughly, waiting for me to try it again so they could punish me. I waited a week for their suspicions to die down and then was able to acquire ten pounds of tobacco. With the tobacco, I bought cigars and snuck out of the barracks for the seven mile walk to Halina's camp. I confidently walked to where the commander resided, dropped off the box of cigars for him, and left. The next day, I again went to Halina's camp and found that the guards simply let me in. The commander stated that while I was trouble, I was allowed in the camp once a week, as long as I was not a nuisance and gone before night. That seemed simple enough, since I had been doing just that for a number of weeks already. I am so incredibly grateful that I found her and can see her so often. I can only hope this war will be over soon.

George

December 26, 1944

Dear Wilk,

Christmas has just passed and I can honestly say it wasn't terrible. We did not get any extra servings of food and were not allowed to leave the camp, but we didn't have to work. Unexpectedly, Halina showed up to the camp, carrying a giant sack on her back. Because we would be shot if either of us crossed the entrance, we spoke through the fence. She explained to me that she did not want me to go hungry, so she slaughtered one of the several cows at her camp and prepared it for me. Then, she strongly threw the sack over the fence. It was so heavy that there must have been at least twenty pounds of meat! I couldn't believe she carried it the whole seven miles in the snow for me! There was so much meat that I ended up sharing all of it with the others in my barrack. They were so grateful that I shared with them, and I was grateful for Halina. She would do anything for me, and I would do the same for her. This war appears as though it will never end. When it finally does, Halina and I will come visit you.

George

September 3, 1945

Dear Wilk,

The war is officially over! After six long years it has finally ended! The day the war was declared over, several of the men including myself decided to take pictures with each other, not sure if we would ever see each other again. After the pictures, as I was making my way towards Halina, who was standing by the entrance, a Russian soldier blocked my path. Noticing my German work uniform, he kept shouting at me, thinking I was a German. Suddenly, he whipped out a gun from his belt and started pointing at me. I thought for sure that after everything I had survived, I was going to die from a misunderstanding on my last day of freedom. However, before the Russian could do anything, Halina came out from behind him and hit the gun out of his hand, putting herself in danger. The rest of the men around us then pinned him to the ground. Wilk, this incredible woman is going to be my wife, I know it. We are willing to risk our own lives for each other. I believe that is what many people call soul mates. As soon as we get back to Poland, I plan on marrying her and

spending the rest of my life with her in America. I know, we don't have the money yet, but we will. I will do whatever it takes to create a happy and safe life for her. I love her more than anything, and I know she feels the same for me. I hope to see you again soon!

George

March 18, 1951

Dear Wilk,

Remember after the war how I worked on a tulip farm? Well I then decided to rejoin the English army. At the time, it seemed like a good idea—it wasn't. I was a heavy equipment driver and was still being treated like dirt. I waited for five years for my sponsorship to the United States. You would think that when I got the sponsorship I would be able to pick up and go to America. Wrong. My first plan of action was to get married to Halina. I asked my officer if I could go on leave and he refused. We got into a huge altercation, which resulted in me hitting him in the head with a lead pipe. The officer was knocked out cold. When he regained consciousness, he sent me right to court. At court they stripped me of all my army badges, leaving me with no proof of my service. I was sent to jail for three days and then I was free of the English Army. I went straight to Halina, got married, and waited at the American console to accept our sponsorship. I wasn't quite sure what to expect when I had walked in on a cowboy from Texas, America with his feet up on the table looking directly at me. The cowboy asked why I wanted to go to America, and then he proceeded to pull out a large stack of papers from the desk. Can you guess who they were from? The English Army! I couldn't believe it. The cowboy asked how I felt about the English, and once I had given him my honest opinion, he ripped up all the papers. And that was it. I was handed five dollars and a plane ticket. So here I am now, sitting on an Air Force plane in Germany waiting to take off. I will write to you from America next time!

- George

May 4, 1951

Dear Wilk,

We are here! In America! When we first arrived at our sponsor's house they weren't the most welcoming (slightly due to the fact that they didn't know Halina was pregnant) but eventually they warmed up. We just bought our apartment in Patterson, New Jersey and are pretty happy to be here. There's a great load of discrimination and no good quality Poland food, but we are making do with what we have. You should try the bread here. Its garbage, nothing like the bread at home. I work every day at a nylon factory while my wife stays home and takes care of the boys. I also still miss my first job when we moved to America. I used to be quite the belt buckle maker and could engrave any gun given to me. People went nuts for my products! I'm still considering doing it on the side (who wouldn't want more money right?) When my wife and I go on our Sunday walks everyone says hi to us and even knows us by name. My wife and I also love going to the movies once a week. One week, however, I wanted to go alone (everyone needs alone time, am I right?). I went after work one evening and on my way home I ran into a group of African American men. They asked me for all my money, but unfortunately all I had on me was my new paycheck. The man went back to his group of friends. I had no idea what my next move should be, so I stood there waiting. Next thing I know, they told me to come with them, so I thought "why not?" and followed along. Let me tell you, they took me out to nice restaurants, paid for my meals, took me to bars, got me a little drunk (I'll be honest), and even offered to walk me home. It was great! So unlike all the horrible stereotypes I had heard about. Well I thought so—as we walked home they had asked me for my paycheck. I gave it to them, considering they

had just treated me to so much food and so many drinks. We got to my front door, rang the doorbell, and Halina answered. She was extremely confused as they explained our night out on the town to her. As I approached the door, the man handed something to my wife-- my paycheck. So that was my first experience with African Americans in America. Pretty crazy, huh? I'm starting to think the stereotypes put on people are extremely false.

Send my best to Poland,

George

June 12, 2001

Dearest Wilk,

After all the letters I've written you I just realized I have yet to tell you about our sons! They are grown and on their own now, so I will fill you in on all the in between.

My oldest son George was actually born in Germany right before we came to America.

Once we came to America, he decided he didn't like the name George and wanted to be called Jersy (as you know, George in polish). My wife and I were fine with this change.

Anyways, a few years after we moved to America we had our second son Richard. Jersy and Richard grew up ruling the neighborhood with their other friends. Because my wife and I were always so busy, the streets raised them. Of course we had our moments, but they learned all the important life skills through the real life situations they were put in. Both my boys went to Patterson public school. Jersy had a tough time keeping up with school, keeping jobs, and getting into gang things. Eventually one day I walked into his room, made him put on a suit, and enlisted him into the Navy. This was the best thing I have ever done for him. Jersy worked his way up to a Petty Officer for twenty-two years! After seeing his older brother be so successful, Richard decided to enlist as well. He became part of the Air Force and was very successful. Both Richard and Jersy fought in the Korean War together! After the war Jersy went back to gang things, but he was too old for me to have control. Richard came back, went straight to college, and then got a government job. Jersy eventually became a manager of a trailer park, got married, and had one kid. Richard still lives in Patterson, New Jersey with his wife and two sons. Enough about them, here's a little about me. We still lived in Patterson at the time. I worked as a YMCA leader for a little, then a chimney-sweeper—just a bunch of little jobs here and there. Halina is doing well. She still refuses to let me buy her any gifts, so I have resorted to leaving her random presents in her drawer and pretending that I had nothing to do with it. We're currently debating moving to Charleston, South Carolina once I retire.

Send my love to Poland!

George

1990

Dear Wilk,

Well we did it! I retired; we packed up our home in New Jersey and moved to James Island! We have a big white house and turned the garage into my workshop. I started making clocks (yes I'm still painting) and my business is starting to take off! People love all my different styles of clocks. It's a pretty nice life down here. Halina has been very happy here. Her favorite part of our home is the sunflowers that have started to grow all around. We have the nicest neighbors as well. Heather lives next door to us with her husband and three kids. Since we don't see Richard or speak to Jersy very often anymore, they have become almost like a second family to us. We are always all together and having big family dinners. Halina and Heather act as if they are sisters. As I said before, it's a great life down here.

- George

September 23, 1998

Dear Wilk

I am truly sorry I haven't written in so long. To be quite honest, things have not been running so smoothly like they were in my last letter. My beautiful wife was diagnosed with Alzheimer's disease a few years back. At first it was not that bad, a couple forgotten item placements and names. But once it started to get into the second and third stages, the doctors made it more clear that she needed to be taken care of a lot more. I decided to take on the role as her primary caregiver. I owe it to her after all. We have been through too much together-- not to mention she saved my life two times already-- for me to even consider letting someone else take care of her. I don't want to sound like I am complaining because it was my choice to be her caregiver, but I will be honest it's getting harder to manage. The constant care she requires is starting to take a toll on me mentally and physically. Finding time for myself is becoming a struggle. Everyone, doctors, my sons, even Heather have advised me to start looking into homes for her to live in where she can be taken care of by multiple nurses. I just can't bring myself to do it. I know deep down putting her in a home would be better for both of us, but I just don't want to let her go or have her feel like I have given up on her. I still need her as much as she needs me during this time of her life. The doctors are also starting to worry about me. They say it's common for the caregivers to experience feelings of depression and are trying to have open conversations with me about it. They think maybe I should talk to someone or take medicine. I just can't think of anything other than Halina right now. She is the main focus, as she has always been. I just want to make it clear to you that I do not mind taking care of her, sometimes it's nice being able to let out my feelings and thoughts to someone I know I can trust.

I hope you are doing well.

- George

February 9, 2006

Dear Wilk,

I made the decision. Halina will be moving into her new home soon.

-George

October 31, 2009

Dear Wilk,

I just returned from visiting Halina. I brought her a light up pumpkin to keep in her room in the spirit of Halloween. I wouldn't say things are better, I still feel lost without her at home, but Halina seems to be doing much better here. I visit her every day, spend the day with her and still take care of her. She is still the Halina I fell in love with at the age of 13. Recently she developed an admirer in the home. This man refused to leave her side from the moment she woke up to the moment she went back to bed. It's been going on for so long that I have had to tell the main nurses to move him away from my wife. They eventually did, but that still stop it from going on. I got a call yesterday that she had beaten him up with a rolled up magazine! Of course I found this phone call to be much less of a problem and much more of a reassuring moment. It's nice to know she's still got that same side to her somewhere. This horrible disease is starting to take more and more control. I enjoy my daily visits with her very much, I try to take in every second I can get when she has her moments of clarity. Remember how I used to play La Paloma in the bands during my musician days? It's still Halina's favorite song and we listen to it each day.

During the song it seems to entirely bring her back and we have the nicest moment together. I will continue to cherish all of these moments with my beautiful wife. While Halina has been living in the home, I moved to a one bedroom, one bathroom condo in Mount Pleasant. It's not much, but I wasn't going to live in my big home on James Island anymore. Maybe now I can go back to painting as well.

- George

January 29, 2013

Dear Wilk,

I am writing you with sad, sad news. Halina has passed. For the most part, I am at a loss of words. However, I know she is in a better place now, rid of disease. We had a beautiful reception for her at my house. Everyone came: Heather, all the nurses, all the generous people from Odessey Hospice, and of course my sons. I was even okay enough to say a nice speech about my wife. I wish it could have occurred in Poland. After the reception I took my wife's ashes and sprinkled them along the beautiful Charleston shores. I miss her more and more as each second goes by.

-George

Dear Wilk,

The months have started to pass a bit quicker. I can't believe I am about to turn 92 in a few short months. I am doing better, the only main difference is my hearing is starting to fade. I'm making due with my life these days. I spend a lot of time emailing people back in Poland and looking up Poland on the computer. Many people think us old people struggle with computers-- it's not rocket science! I started playing the musical saw again, I practice for almost two hours each day. Sometimes I take walks around my complex (I think when I moved in an email or letter went around about me because everyone seems to know who I am), or sometimes I sit outside and take in the sun. After my wife got sick, I signed up for the meals on wheels program so when my food gets delivered I spend some time talking to the nice people who bring it. Let me tell you Wilk, the food in the last years has gotten worse. Sometimes I barely even eat it! Oh yeah, I just bought myself a brand new car! It's a beauty. I thought to myself one day, what am I going to do with this money? So I got myself a car. Other than that my life has become much simpler, it feels as if I am just getting by. Sometimes I think to myself that I'm ready to be with my wife again. I still miss her with every inch of my body. I also miss Poland a lot these days. Whenever I look through old pictures and think of all the times I had there I want to jump on a plane to Poland! Other than that Wilk, things are okay, almost better.

- George

SAMPLE NARRATIVE #2

This is a similar narrative (of a caretaker to someone with Alzheimer's), but it was written by Honors students, and in a more traditional narrative format. Although these students experimented with various formats, they felt that the interviewee would most appreciate a linear story of his relationship with his wife. They included extensive psychological research about caretaking and Alzheimer's and also drew on May Sarton's Endgame and Rita Charon's Narrative Medicine.

Transcribed Narrative of Rose and Wilbert

Healing Narratives, Rogers and Hanna

25 April 2014

On the Background of Their Lives

When pulling up to Rosa-Lee and Wilbert's home in Goose Creek, South Carolina, one is greeted with a phenomenal portrayal of traditional Americana. The home is situated in the middle of a sizeable yard framed by several overhanging, shady trees and flowering shrubbery. The yard is further decorated with flags and small, happy figurines. The home itself is brick, and is in the ranch style with a sizeable picture window in the living room that overlooks the front yard. The house is adorned by a one-car garage off to the side, completed by a big red pickup truck parked directly in front of it. An embroidered image of a flag flying above the words "God Bless America" hangs on the front door, next to a sticker saying that a Navy veteran lived on the premises. You can even hear a little chihuahua inside alerting the couple to your presence when you stand on their front porch. It is a perfect image of the suburban American dream that is recurrent in 1950s popular culture, with the only detail missing being a literal white picket fence.

Meeting with Rosa-Lee and Wilbert in their charming residence felt like a journey through time. They were so welcoming, and were able to converse with eloquence and ease. Few people put similar effort into such meetings, and the couple immediately made a lasting impression on us. One of the many striking aspects of the couple was the visible sincerity of their love for one another, which has lasted throughout the many twists and turns of their marriage over the course of six decades. The depth of their emotion was evident in the vivacity that exuded from Wilbert as he fondly recalled stories of his life with Rosa-Lee and, in the way he continued to care for his wife in the face of her diagnosis of Alzheimer's

disease. His care for her brings to life his vows of “in sickness and in health.” Seeing such intense and unwavering love and devotion is what, I believe, gave the impression of traveling back in time: in the modern generation, many permutations of marriage have evolved with an increasing prevalence of divorce, but Rosa-Lee and Wilbert keep alive the tradition of lifelong romance and dedication to their spouse. To see Wilbert care for Rosa-Lee with such patience and deliberate care, and to see the loving way Rose regards Wilbert despite the progression of her dementia, fills one with awe at the strength of their relationship and verity of their love.

Born in Noxapater, Mississippi and afterwards moving to North Carolina, Wilbert joined the Navy after graduating high school. As an enlistee in World War Two, Wilbert traveled throughout East Asia during his late teenage years. He was stationed on surface ships, and fondly recalls his many exotic experiences in these countries. Wilbert speaks very highly of his experiences with the Navy, and through his stories one is imbued with his sense of patriotism. He is very eager to recount details of his duties on surface ships and various aircraft carriers, and the many stories about aircraft carriers, jetplanes, and the shenanigans the enlistees and commanding officers used to get into.

Upon Wilbert’s return to the United States, he was stationed on a base in North Carolina. The base was several hours away from the town in which one of his sisters was completing her nursing degree. During one of Wilbert’s leaves, he went to visit his sister with several of his Navy friends. He was introduced to one of his sister’s good friends, Rosa-Lee, who went by “Rose.” Wilbert recalls that he and Rose began “going steady” immediately, and his sister felt pride in setting the two of them up so successfully. Despite her relationship with Wilbert, Rose, being a very independent woman considering the cultural tone of 1950s feminism, was determined to finish her nursing degree before she was married. Thus, she and Wilbert dated throughout the end of Rose’s nursing school, with Wilbert driving to across North Carolina to see her every opportunity he had. The friendship between Wilbert and Rose that

underlay their marriage was evident when Wilbert recalled Rose's determination to fulfill her career goals; he spoke of her dedication with pride, and reminisced about the many road trips he took to see her with a wistful joy. This was particularly endearing and humbling to behold since (I imagine) so many young men would not have been as patient for his fiancée to finish her education at that time. Such dedication and functionality set the foundation for their mutual support in a successful marriage that has since lasted the better part of six decades.

On Family Life

The young couple moved from North Carolina after their marriage to North Charleston, South Carolina. Wilbert was stationed at the Naval bases in the Charleston area, while Rose was a surgical nurse. They both experienced great success in their careers, and Wilbert continued to extensively travel with the Navy. Wilbert speaks very highly of the opportunity for travel, including working on an aircraft carrier in the picturesque New Orleans area, as well as out in the frigid waters outside of Coronado in California. Soon after the couple moved to North Charleston, however, Wilbert was transferred to Pensacola, Florida. Wilbert and Rose lived in Florida for three years, where Rose took some time off from her nursing career due to the birth of her first two children, her daughters Tana and Maria. The family, then, moved back to the Charleston area after several years, and moved into the Goose Creek residence they call home to this day. Upon their return to Goose Creek, Rose gave birth to their two youngest children: Mitch and Dave, who they have lovingly nicknamed "Boo."

Wilbert spoke with great admiration for his children, and the stories he shared reflect a very secure and loving family dynamic. Wilbert recalls how he was especially involved in the boys' life by acting as a Little League coach, and has many fond memories of teaching the differences between pitching a proper curve and knuckle ball (techniques which he can still explain very eloquently). Furthermore, Rose and Wilbert were very involved in their community; Wilbert helped to construct their current Baptist

church, and he and Rose were both very involved with Sunday school, as both participants and youth teachers.

Besides reminiscing about their involvement with the church and raising four children, Wilbert swelled with pride when recounting Rose's incredible medical knowledge and success as a surgical nurse, as well as the value of her knowledge to their community. Wilbert recalled how a young boy who lived about a block away was diagnosed at a young age with a severe, chronic medical condition (which shall remain unspecified). He tells of how this boy grew incredibly close with Rose and his reliance on her sage professional opinion about his condition. Wilbert says how, even though the boy has since become an adult, he still visits them at every opportunity.

Wilbert was very eager to sing Rose's praises, saying how their community viewed her as the local "doctor," and would feel free to come to her first with any medical ailment. The mutual professional respect, pride, and friendship which Rose and Wilbert shared was not only progressive for the time, but provided the basis for a long and happy marriage.

On Illness

The dynamic of Wilbert and Rose's relationship underwent a drastic change upon her development of Alzheimer's disease, a diagnosis that was shared with both her elder and her younger sister. To be diagnosed with Alzheimer's disease is one of the most devastating labels an individual can receive. There is no possible prognosis because, as modern medicine stands, a cure is yet to be found. Alzheimer's disease is a form of dementia, a degenerative condition that initially affects memory and then progresses to incapacitate the individual in other areas of functioning, eventually leading to death. Alzheimer's disease is the most prevalent of all types of dementia. As the layers of memory are progressively eroded, the individual suffering from the condition is slowly isolated from their environment and the people around them. The identity begins to dissipate and, with it, their ability to maintain the

same kind of interpersonal relationships they had prior to the disease. Exactly which mental faculties remain intact varies from case to case, making the role of the caregiver crucial in being a bridge between the person's past, present and the looming future.

The diagnosis of Alzheimer's completely altered Rose and Wilbert's relationship. Throughout the course of their lives, the two have been many things for each other; friends, lovers, confidants, and husband and wife. Now, they have the added dimensions of patient and caretaker. Across all stages of their relationship, however, is the theme of unwavering and loving companionship. Together, Wilbert and Rosa-Lee raised four children, who themselves are parents and even grandparents. They have lived a life replete with social, environmental, and role changes. You can quantify their time together, 60 years of marriage in August 2014, but there is more to the longevity of a relationship than elapsed time.

To walk into the Slawson residence was to be privileged into a relationship of value. Although the Alzheimer's disease affecting Rosa-Lee has robbed her of vitality in social situations, the nature of good company is such that the person's presence is sufficient to improve your mood. Even in her debilitated condition, she still walks over to him to rub her husband's back. She holds his arm and he stands proudly beside her. When he speaks about his sweetheart and her condition, his eyes fill with tears and his voice begins to break. Wilbert is heartbroken by the disease. He wishes no one to ever experience this awful condition and he there is an unwavering determination to do everything that he can to hold on to her. He still finds that she is somewhere inside the vessel that her body has become. He cannot imagine his life without her. "When you've been married to someone for as long as I have, and she was with you for your entire life, there is no you and without her."

All of the changes brought about by the disease have been challenging but they have also served to highlight the beauty of what has remained. For example, in one of the visits to the Slawson residence, Wilbert held Tinker, the smallest dog I have ever seen, on his lap. He and Rosa-Lee were quietly holding

hands under the table. I could feel the love in that moment and it did seem like a brief glimpse of the previous normalcy of their lives. A man and a woman united in holy matrimony, rather than a man caring for a woman suffering from Alzheimer's disease. After seeing that, it became a little clearer to me how Wilbert was able to cope with the loss of the details in a relationship to Alzheimer's disease since the big picture, their irrefutable love, remains. Maybe he is still living with her in the same way that they did in the past, but with countless changes to their home and lifestyle reflecting the limitations of her condition. He does not want to have Rose move into a nursing facility because he may lose the remnants of their relationship by separating her from their home. He wants to remain at their home, with her,, whilst trying to adapt to the daily changes. Adjusting to Rose's progressive diagnosis of Alzheimer's disease is, without doubt, one of the most difficult permutations their relationship will have to undergo.

How does he find respite? How does he bear the emotional load of caring for the love of his life as she begins to lose grasp of their reality? In investigating these queries, we found that Wilbert only requires hospice care to intervene for Rosa Lee about once every week. The rest of the time, he looks after her by himself. He is tremendously diligent and disciplined with their routine. He usually wakes up about an hour or two before she does. "Waking up before her is the most productive part of my day. I do all the chores I can and whatever else I need to do before she wakes up. Once she is awake, it's all the attention on her and I cannot leave her on her own." When I asked him what he does with her when she is awake, he looked gloomily at the table, with his glasses were resting on his brow. His eyes swelled up with tears. "I just watch her. I care for her. I wake up every day for her. I don't know how those people can put their loved ones in a home. I could never do that to her. She is my everything. It's not about what she can do for me; it's about what she means to me."

Coming Home

One of the difficult things, which caregivers of Alzheimer's patients struggle to reconcile with, is that, despite the quality and quantity of care given, patient lucidity cannot be induced and the prognosis of disease progression cannot be altered. This is evident in Rose's case, where she unavoidably exhibits the classical symptoms of Alzheimer's, including confusion and wandering.

"Wilbert, I want to leave the house. I can't get out. Why can't I get out of the house?" Rosa-Lee continually asks after attempting to open up all the doors of the house to "go home," an activity she repeats on a daily basis. She feels trapped in a place that was not her own, despite her living in the same house in Goose Creek for the majority of her adult life. It is a strange reality that she is living, where the familiar slowly becomes novel and unknown and cannot be permanently re-learned. Wilbert patiently reasons with Rose during her outburst, saying "We shall leave at six, hon. It's only 3 o'clock so we have plenty of time. Sit down. Please, sit down. You'll do that for me, won't you?"

When Wilbert answered Rosa-Lee, he knew what he was doing. He knows that she will not remember what he said to her and that she will return to ask the same thing. He has to feed her something that she is satisfied with and, no matter how many times he has to do it, he will continue to work to give her the responses that she needs. As he asked her to sit down, she put her hand lovingly on his chest and replied, "I will. I love you..." He reciprocated the gesture as she walked away. And then, there was the crushing silence of reality. Wilbert's eyes swelled with tears. In moments like this, it is not easy to persevere and remain optimistic. The person you have loved the most, for the course of your life, is in a paradoxical state of existence: she is there and not there at the same time. There is no prognosis and there is nothing one can do but be brave and patient. Wilbert began to cry ever so gently, with a dignified yet tangible fragility to the act. He told us just how difficult it was to lie to her every day, although he does not regret his choice to care for her at home despite the immense internal anguish it brings him. Wilbert showed true strength and courage in his perseverance despite his grief and fear for Rose.

Home is a place of so many junctions and so much meaning that is directly tied to our identity. In a way, after so many years of life, home can be a mobile place that we carry with us wherever we may go. Home is familiar. Home is safe. Home is a feeling. For Wilbert, Rosa-Lee's presence is an essential element to his home. Together, they have raised their children, given parental advice and support in the raising of the grandchildren, and have both enjoyed successful careers as young adults. Having been married for almost 60 years, they grew up together. Over the course of life's journey, each other's presence was the only constant factor from their teenage years until now, in late-adulthood. Rosa-Lee depends on Wilbert to look after her, and Wilbert depends on her just as much from the role of a caregiver. He wakes up, not because he has to care for her but because he wants to care for her and about her. It is so much more than a responsibility. This is his companion, his *raison d'être*, and a seminal part of his identity. In the metaphor of a house, she is the front door. While he holds his own structure together and provides her with the framework to exist, Rosa-Lee represents the pathway to the most important part of Wilbert: his essence. His inner-workings begin and end with her. Within the house, it is all organized into each respective context. The house is undoubtedly red, white and blue, raised from the ground up and consolidated during some of the most important years of American history. But the house is uniquely his, with no two bricks in this world being laid in the same way as any other pair. For something to get in the house, it has to pass by the most important person in his life. Likewise, to exit, it has to go through her. In her existence, she allows him to retain the integrity of his life by providing the direction and secure footing he needs. She is his home port, his safe harbor: she is his life-long companion.

Before closing the door to this chapter of the narrative, we asked Wilbert about anything else he'd like us to know. It did not have to be something that was going to contribute to the writing of their narrative. It was to be something that represented who they were and what they believed in. "I want you to write in your narrative," he glanced smilingly at us, "that I am someone who loves life." This simple statement seemed to give amazing insight to the incredible strength of his spirit. Living life is not about

what you can accomplish or who you can become, nor is it about the goods you can acquire; life is about the way you love it. There is an inherent truth about the statement “life is for the living” that goes beyond the superficial meaning of making the distinction between those who are physically alive or those who have passed. It is, on a deeper level, about those who are active or passive agents in their life. Wilbert is someone who has taken the most pleasure out of anything that life has thrown at him. I am not saying that his optimism is unrealistic or his spirit is unwavering, but his drive is irrefutably relentless. His passion for life fuels his gratitude for the good and builds his endurance for the negative. He lives today with the appreciation that allows him to look forward to every tomorrow and every yesterday. He is free. He is safe. He is home.