Down Came the Rain

A Journey Through Love and Parkinson's Disease

by
Adele and Frank Hensley
with Claire Shrader

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St. Peter's Episcopal Church, 313 Pine Street, Philadelphia, PA 19106.
Contact ceshrader2@gmail.com

Methodist Children's Home of Mississippi, 805 North Flag Chapel Road, Jackson, MS 39209 https://www.mchms.org/

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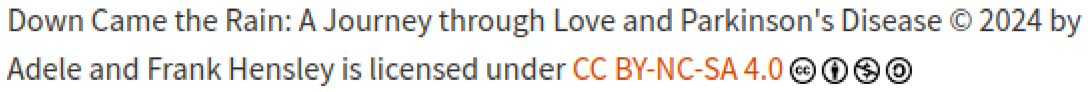

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Cover photo: Adele Pfrimmer Hensley and Frank R. Hensley, 1992, Aiken, South Carolina. Photographer unknown.

For Clark

Foreword

This is a memoir, a love story, and a tragedy. It is full of happiness, but it does not have a happy ending. It is for people who knew Adele, and for people who didn't. It is my desire that you will know her better, remember her better, and be inspired to love others as she did.

No one can tell Adele's story better than Adele, so as much as possible, I have helped her do that in her own words, which are set in *blue italics*. I have added context and narration so you can follow her story arc, but whenever possible I tried to help her speak for herself. I have chosen to leave in her typos and show her messy handwriting because the decline in her ability to communicate is a big part of what Parkinson's did to her. . . what it did to us. However, I have transcribed where her handwriting is just too hard to interpret. If you can't read what she wrote, just look below it.

Things I wrote in the past are in *green italics*, as opposed to this new text that threads it all together. Other colors occasionally indicate other voices, particularly Claire Shrader, the daughter we never had, in purple and a contribution by Clark in red.

Frank Hensley, 2024

Adele's Foreword

When I write for real . . . I write in the red folder. It's red because I'm bold—I'm bold, I'm stepping out of the retiring safe place where I'm sure I'll be loved, and into the strange place where I'm not sure of anything but that I may be(come) myself… Life lived intentionally is hard but strong. I want to be strong—I want to be independent but connected. Strong but vulnerable.

How do you write stories when you've always read them, listened to them, received them? How do you become a creator, not just a repeater of stories? What is the story that I want to tell? What is the story that I have to tell? I think that part of the story that I have to tell is the story I've been telling myself when I'm with Natalie[1]*. It's the story of a little girl whose world changes and who deals with that change in the way she thinks is best. Only how can a little girl know what the consequences of her choices will be? How does anyone ever know? Vance Tucker*[2] *told me that you'll look at your life when you're 50 and still you won't know if you're doing the right thing. Am I? I know that some of what I'm doing is my right thing. I think that this writing can become the right thing…*

I don't know if any of these pages will be worth keeping or not. All I know is that I'll never create anything if it has to be perfect. I'll never learn how to help myself through hard times if I won't let myself experience them.

I am creative, I am funny, I am interesting and insightful. I may or may not have anything to say that people will pay attention to. I can do this for "people" or for attention—that's why I need the museum[3] *or something like it. I have to do this because I want to find the story. I feel like it's lurking just beyond my mind. What will the story be? Let us see!*

Adele Pfrimmer Hensley
22 May 1997

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[1] Natalie was a professional counselor Adele was seeing.
[2] Dr. Tucker was one of Adele's graduate school professors.
[3] Adele was working as a museum educator at the time.

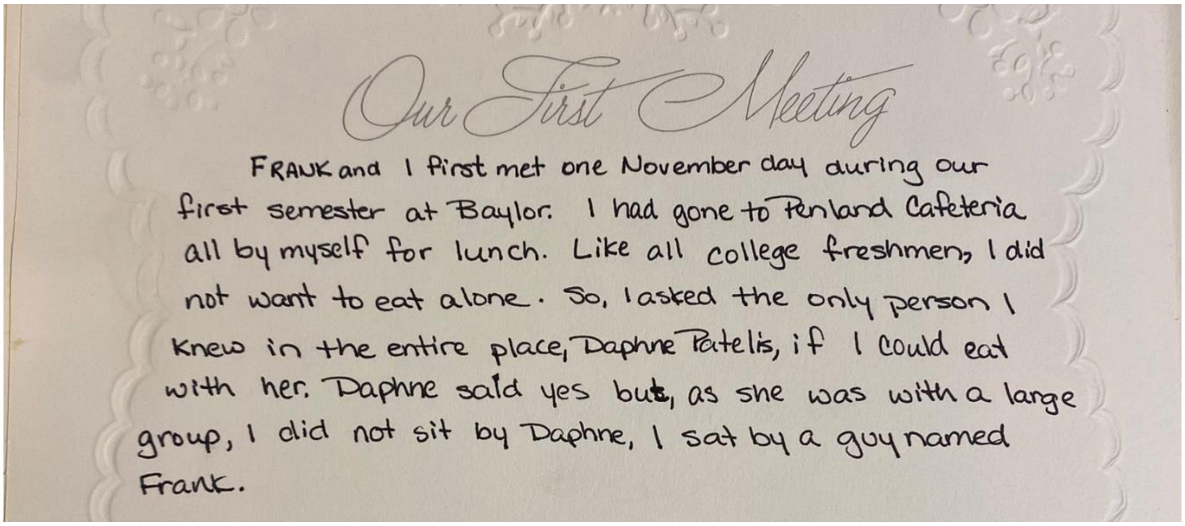
I. Texas Rain

August 1983

It felt like a step into the abyss. For an introvert, stepping out of the cafeteria line into a sea of occupied tables with no familiar face in sight can be terrifying. I felt conspicuous that first week of classes at Baylor as I moved slowly, scanning for a place to sit alone, or sit with someone . . . anyone . . . that I knew. I was paralyzed by the idea of grabbing a random single empty seat surrounded by strangers. And then I spotted Daphne, a girl I knew from my Welcome Week orientation group. Daphne would rescue me! I had no idea that the next moment would change my life forever. Daphne was having lunch with a group of girls from her dormitory hall, but she welcomed me when I asked to join her. Within moments of sitting down to join them, I heard the most beautiful laugh. I heard my Adele laugh for the first time. That's how I remember it.

May 1987

But memories are strange things when we share them. Here's how Adele recorded our meeting four years later in our wedding album:



Our First Meeting

FRANK and I first met one November day during our first semester at Baylor. I had gone to Penland Cafeteria all by myself for lunch. Like all college freshmen, I did not want to eat alone. So, I asked the only person I knew in the entire place, Daphne Patelis, if I could eat with her. Daphne said yes but, as she was with a large group, I did not sit by Daphne, I sat by a guy named Frank.

Frank and I first met one November day during our first semester at Baylor. I had gone to Penland Cafeteria all by myself for lunch. Like all college freshmen, I did not want to eat alone. So, I asked the only person I knew in the entire place, Daphne, if I could eat with her. Daphne said yes but, as she was with a large group, I did not sit by Daphne, I sat by a guy named Frank…

It's the same story. Except it isn't my story. Except it is.

Anyone who knows us knows that Adele was fearlessly social. By the first day of classes, she'd been at marching band camp for a couple of weeks and knew the names of almost everyone in the band. Plus, she'd been through the Welcome Week orientation, too. And by November, she knew the names of everyone in her classes and all the girls who lived on her hall in South Russell dormitory. The idea that she'd have nobody to eat with in November is hard to believe for someone as gregarious as Adele.

But I'm not here to correct the record. I'm not here to dispute the facts. When you love someone, you see the world from their perspective as much as your own. I have no doubt that the way she told it is exactly how she remembered it – because for both of us, it was true. It's my story, but it's our memory. When you share memories, you absorb each other's stories. I'm here to celebrate that these memories are our memories, and sometimes I don't know which are hers and which are mine, but they are all ours. Ours to blend. Ours to treasure. Ours to share with you.

1983-1987

I felt awkward around girls. I had dated one girl in high school, but she was a year older than me and went off to college and broke my heart. So, when Daphne introduced me to Adele, I wasn't a smooth talker who could just approach a girl and start a conversation. I needed a credible pretense, or I'd be a tongue-tied mess. Not long after that lunchtime introduction, I went to the cafeteria for breakfast. The cafeteria was usually deserted before 8:00 AM classes, but Adele was there, sitting by herself, eating, and reading Mere Christianity by C.S. Lewis. I had read that book a few months earlier. Unlike his

Chronicles of Narnia, it's a heavy read. When I saw Adele reading it, my interest in her increased, because I marked her as intelligent and a girl of my faith tradition. So, I approached and struck up a simple conversation, "When you're done with that book, may I borrow it?" (I wonder what C.S. Lewis would say about me using his apologetical essays as a pretense to get a date with a girl.)

So that request to borrow a book was the beginning of our regular discourse… a thirty-nine-year dialogue about life and love, faith and doubt, hope and fear. Over the course of our four years at Baylor we spent every summer and Christmas apart. There was no internet, and long-distance phone calls were expensive, so we wrote a lot of letters. Those letters tell the story of how we fell in love and how we changed our minds about our futures, and how those futures became one… I'm so glad we both saved those letters, more than 200 of them, so I could use them to tell you about falling in love with Adele.

Mixed into the arc of our lives together, however, are some memories that are not of grand decisions or formative events, but just playful or funny anecdotes that add some sugar and spice to the daily flow. These are shared memories that come up time and again…touchstones that remind us how we came to be…us.

One day, very shortly after that first lunch together, we crossed paths again in the cafeteria. I was eating with my roommate and oldest friend, Kurt (we've now passed 50 years as best friends). Adele approached someone at an adjacent table and stood talking to them with her back to me and her hand relaxed at her side. On a whim I scooped up a spoon full of red Jell-O, and carefully maneuvered it so that it hovered just above her curled fingers. A slight tilt of my wrist and it would drop into her hand. Kurt, watching intently, asked under his breath "Do you know her?" and I whispered back, "A little."

"Do it! Do it!" he urged me.

But I chickened out.

Spring 1984

Calculus is not romantic unless you're a nerd. One of our first classes together was Calculus II, and early in the semester I asked Adele if she would study with me. At first, it wasn't about calculus at all; it was just a reason to spend time with her. But soon, probably because during our "study time" I was too distracted, I began to struggle. I failed the first exam. And the second one. And the third one… Eventually I decided to drop the class. I re-took it my Senior year and the professor gave me a generous grade I hadn't really earned. Whew!

For decades I have used my calculus story as an example for my students, telling them that it is important to choose a study partner carefully. "Study the right amount with the right person, but remember you'll be working on your own during the exam." I always point out that I blamed my study partner for my failure, because she wouldn't slow down and explain each step of the homework problems. The punchline is, "It was her fault, but I got revenge on her. I married her."

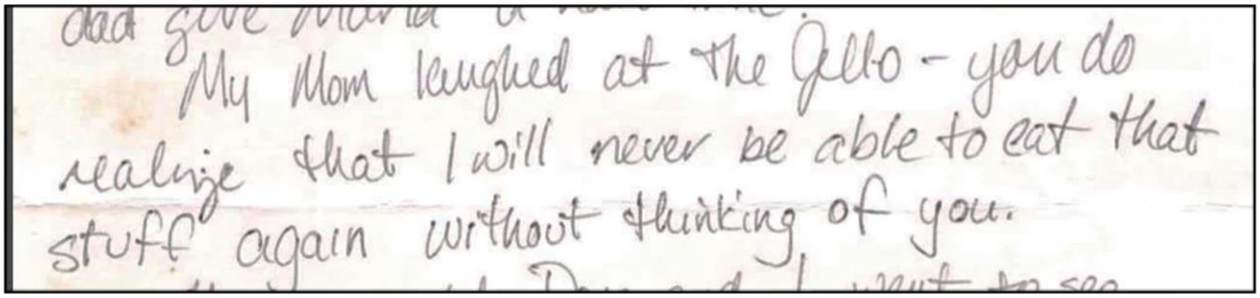
Despite the fact that I have suppressed a lot of bad calculus memories, there is one thing that draws me back. In high school Adele had a senior portrait taken while wearing a red dress with tiny white polka dots. And, for whatever reason, I have very distinct memories of her wearing it to calculus class. She sat to my right, about 4 seats away, and when I see that portrait, I'm instantly transported to a classroom in the Sid Richardson Science Building. That same semester we sat next to each other in Old Testament class. I have no memory of what she wore on those days, probably because she was right there next to me, within a whisper's reach. In my mind I can still hear Dr. Patterson's resonant bass voice, "The theme of the Old Testament is simple: Obey and prosper; disobey and perish!" But in calculus Adele was too far away, and my eyes and my mind would wander away from Dr. Tidmore's chalkboard every day, and for whatever reason the red dress imprinted in my brain. Integral calculus was integral to falling in love with her.

* * * * *

After a few weeks getting to know each other, Adele and I began eating lunch together frequently. Kurt was often there, too. At one point, Kurt told Adele about the Jell-O incident, and she stated in no uncertain terms that had I done it, she'd probably never have spoken to me again.

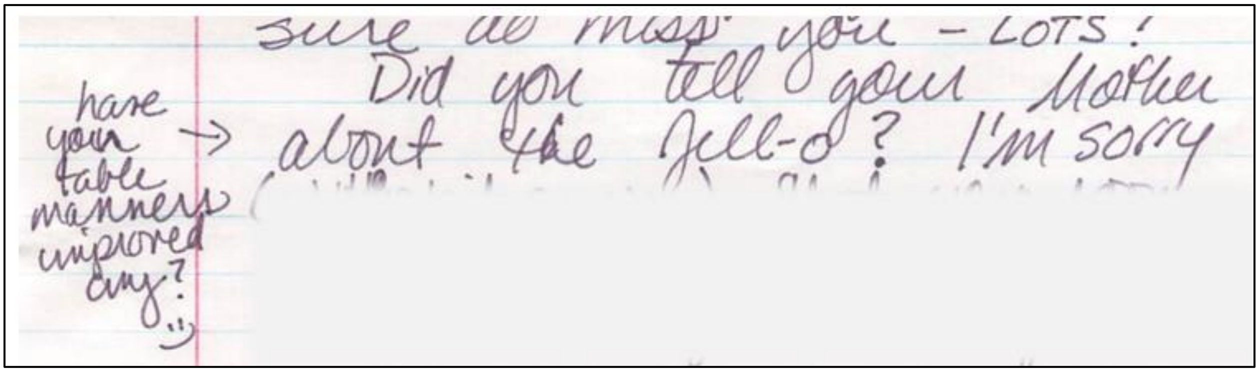
Adele had broken her watch, so she got into the habit of checking my watch toward the end of lunch, so she wouldn't be late to her next class. Rather than interrupt a conversation, she would often just reach over, grab my watch, and rotate it toward her view. I was oblivious to the possibility that the broken watch was all a ruse to make flirty physical contact, or I might not have done what I did…

One day near the end of our freshman year, I realized that I expected her to reach for my watch, and I felt like I finally knew her well enough to get away with some mischief. So, I prepared by filling a spoon with red Jell-O and sliding it under the table. Keep in mind, that I didn't choose Jell-O from the buffet all that often, so this was pre-meditated, not spontaneous. I had both hands in my lap, so when Adele reached to check my watch, I grabbed her hand, turned it over, and filled it with red Jell-O. I don't recall what she said, but she didn't laugh as she smeared that Jell-O down my pants leg. At least, not then. It probably took a few days for her to laugh about it. But the Jell-O incident came up in conversation over and over. Here are some exchanges from our letters in May, after we parted ways for the summer:



My Mom laughed at the Jello – you do realize that I will never be able to eat that stuff again without thinking of you.

… My Mom laughed at the Jell-O – you do realize that I will never be able to eat that stuff again without thinking of you.



Sure do miss you – LOTS!

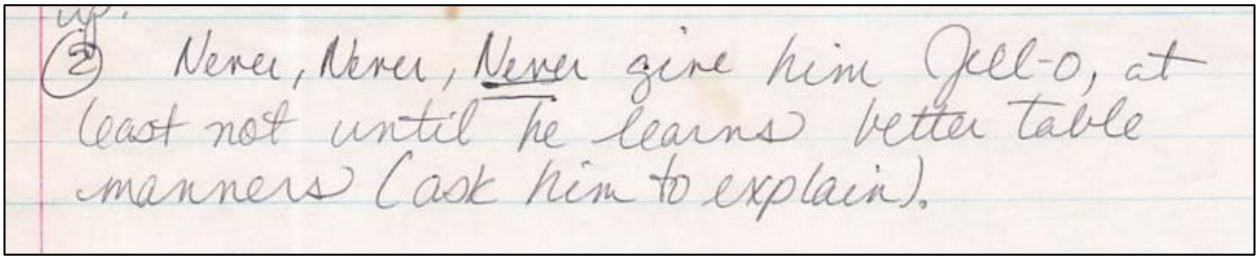
Did you tell your Mother about the Jell-o? I'm sorry

have your table manners improved any? :) →

[redacted]

… Did you tell your Mother about the Jell-O? (Have your table manners improved any? ☺[4])

So then, Adele wrote to my mother about the Jell-O!



② Never, Never, <u>Never</u> give him Jell-o, at least not until he learns better table manners (ask him to explain).

Never, Never, <u>Never</u> give him Jell-o, least not until he learns better table manners. (Ask him to explain).

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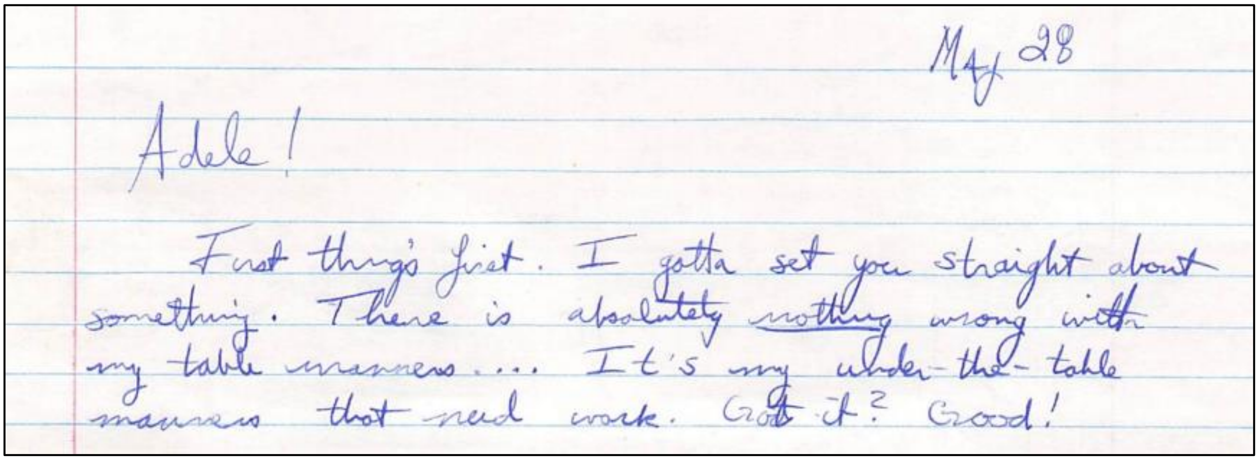
[4] Adele often punctuated her hand-written letters with smiley faces. She was into emojis before there were emojis.

So, I had to defend myself:


May 28

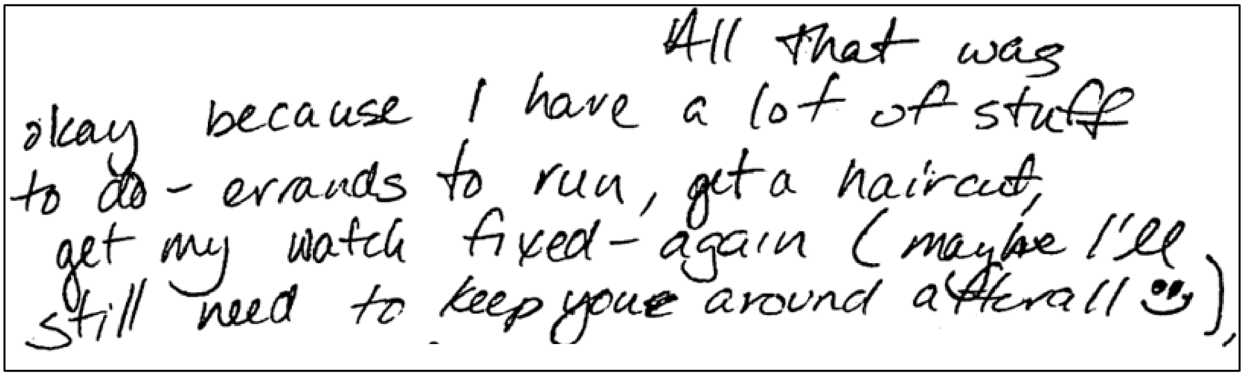
Adele!

First things first. I gotta set you straight about something. There is absolutely <u>nothing</u> wrong with my table manners . . . It's my under-the-table manners that need work. Got it? Good!

Adele,

First things first. I gotta set you straight about something. There is absolutely nothing wrong with my table manners . . . It's my under-the-table manners that need work. Got it? Good!

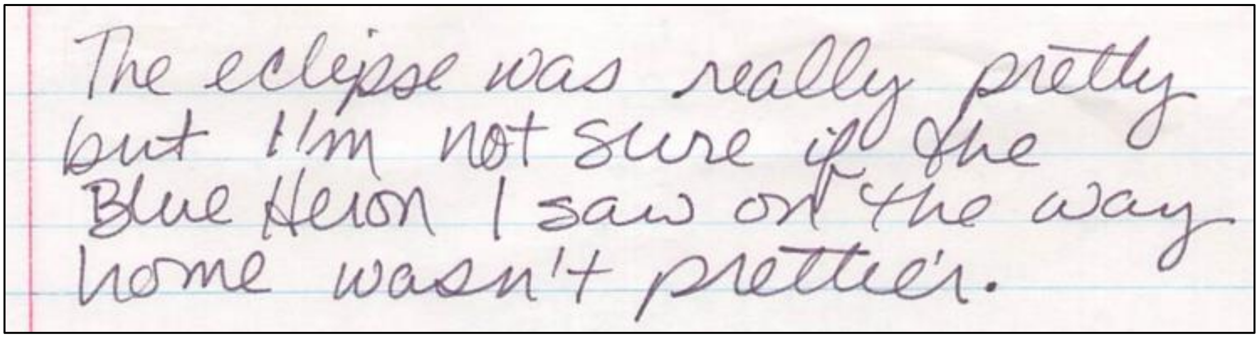
For decades afterward the Jell-O story has been the source of lots of laughter, some indignation, and some fond recollection of the beginning of our love. Here's a snip from a letter Adele wrote me the following January:


All that was okay because I have a lot of stuff to do - errands to run, get a haircut, get my watch fixed - again (maybe I'll still need to keep you around after all ☺),

All that was okay because I have a lot of stuff to do—errands to run, get a haircut, get my watch fixed—again (maybe I'll still need to keep you around after all ☺).

My father once told me that if I wanted to really know where I stood with a woman, I should sneak up behind her and kiss her on the neck. I think my Jell-O method works, too.[5]

So, Adele learned a lot about me through Jell-O. And I learned about her through her letters. I have no idea if I even paused when I read this (May 31, 1984):



The eclipse was really pretty
but I'm not sure if the
Blue Heron I saw on the way
home wasn't prettier.

Did I know then what Adele was telling me about who she was? I fear I may have read past that without a second thought, but perhaps it motivated me to know her better. I don't recall. But today I know the depth of her fondness for the sky, her deeper love of birds and insects and flowers, and how she loved sharing all of those with people. Adele's love for nature and her desire to share it were evident all the way back in her 11-year-old heart:

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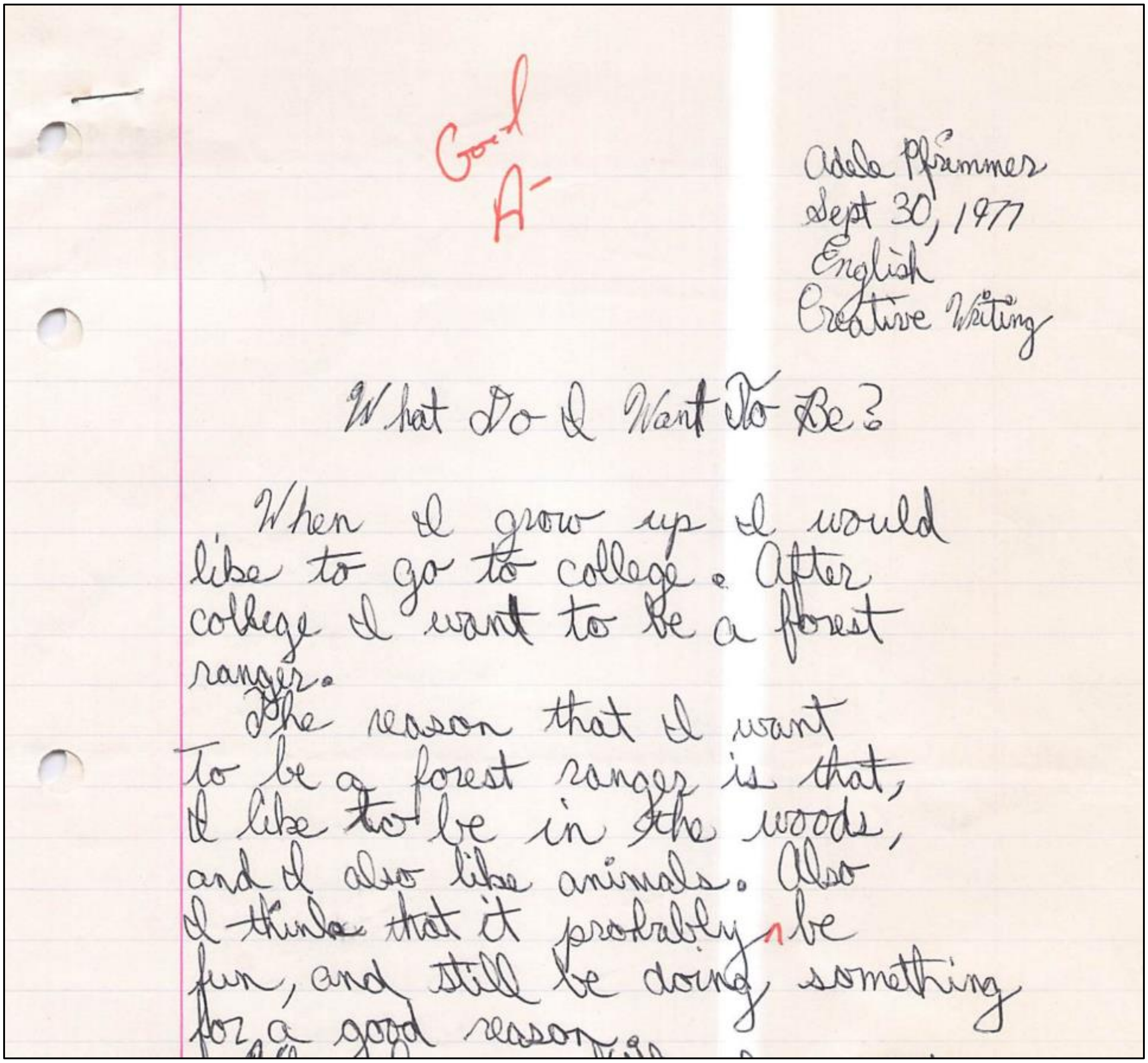
[5] A few weeks into this project, after I had written the Jell-O story, I was struggling with how to write these memories better. I listened to a short podcast about writing memoirs, and one thing became clear: that memoir is not about narrative as much as it is about emotional connections. I knew instantly that this was why parts of my writing were so much better than other parts. Yesterday, some six months into working on this, I noticed one of Adele's books that I had set aside to give away. It is called Old Friend from Far Away by Natalie Goldberg. The subtitle screamed at me: The Practice of Writing Memoir. I snatched it off the shelf, thankful that nobody had claimed it, and began exploring it. It offers various exercises to follow, as practice for writing about memories and emotions. A writing prompt on page 17 says "Tell Me: Tell me everything you know about Jell-O. Go. Ten minutes. Let it rip."

Adele's book about how to write a memoir has a writing prompt that's perfect for me to use to write OUR memoir – I just didn't find it soon enough. Maybe I better slow down my efforts at narrating her story to read this book.



Good
A-

Adele Pfrimmer
Sept 30, 1977
English
Creative Writing

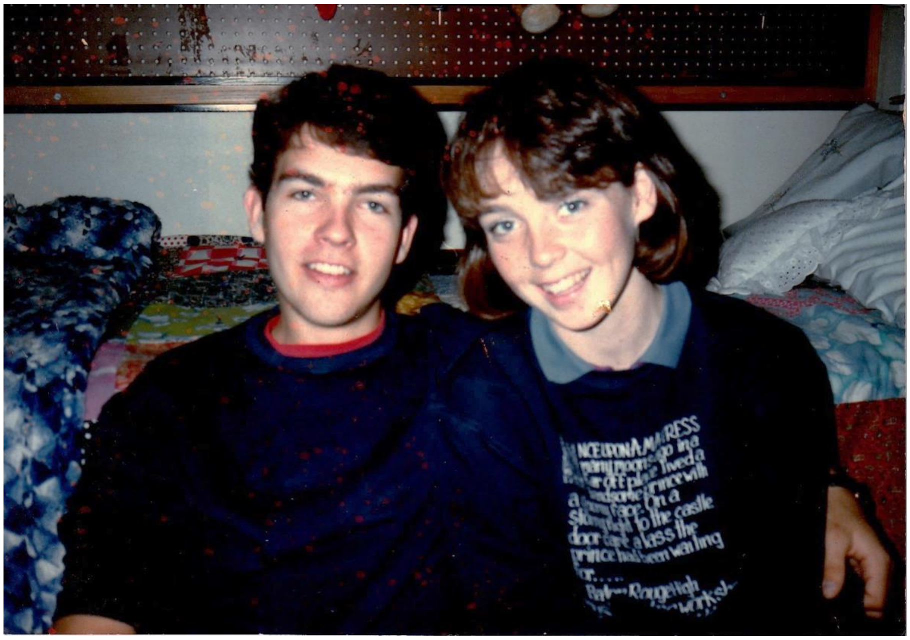
What Do I Want To Be?

When I grow up I would like to go to college. After college I want to be a forest ranger.
The reason that I want to be a forest ranger is that, I like to be in the woods, and I also like animals. Also I think that it probably ^ be fun, and still be doing something for a good reason.

When I grow up I would like to go to college. After college I want to be a forest ranger.

The reason I want to be a forest ranger is that, I like to be in the woods, and I also like animals. Also I think that it probably [would] *be fun, and still be doing something for a good reason.*

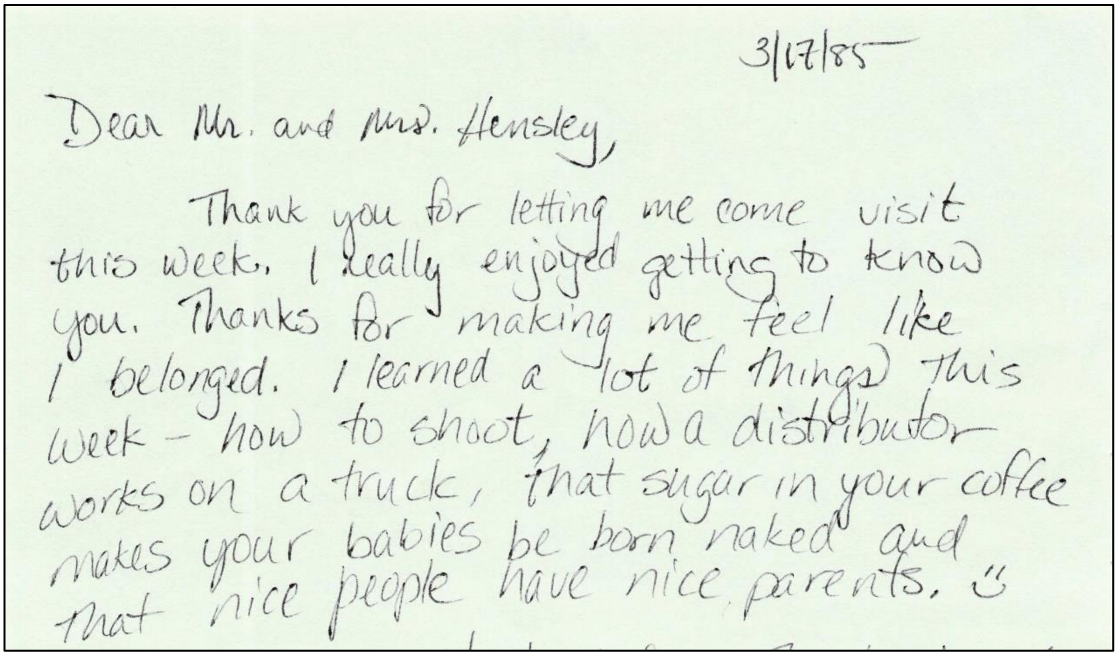
Nearly 40 years later, this seems to perfectly encapsulate something we shared deeply. We both loved the natural world and all aspects of science, but the part that quickened our spirits was the living, breathing part. And every breath of an animal was a breath for us to inhale and share. How could I not be drawn to this woman? She became my forest ranger, accompanying me into the woods and fields, sharing her knowledge and concern for nature. I hope I was a good reason.



Adele and Frank, 1984.

March 1985

I took Adele to Nebraska for Spring Break to meet my family. My family quickly fell in love with her, too. I could tell that Dad approved because he gave her shooting lessons and a hard time. He recognized that she was smart and that I was in love, and that was a winning combination. Adele was a bit more outspoken than most young women he knew, and I think he wasn't sure if he liked that part of Adele, at first. At one point, Adele said something that he disagreed with (I wish I could remember what it was!), and he looked at her and said, "Adele, have you ever had an *unexpressed* thought?" to which she replied, "I'm having one now!" He roared with laughter, and I think that sealed the deal for him.



3/17/85

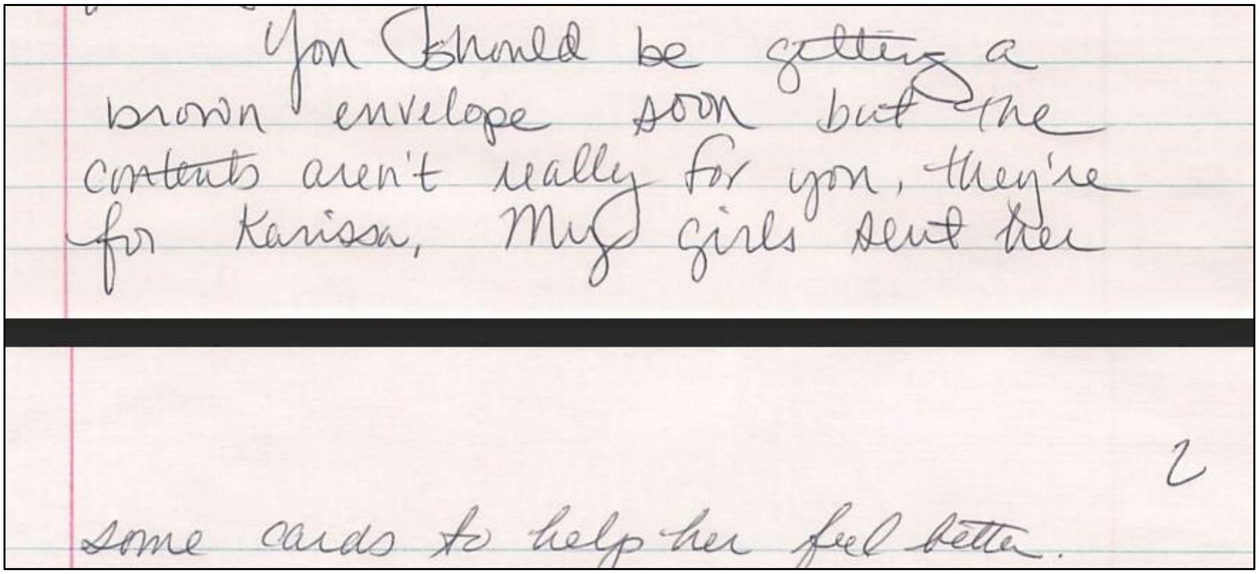
Dear Mr. and Mrs. Hensley,

Thank you for letting me come visit this week. I really enjoyed getting to know you. Thanks for making me feel like I belonged. I learned a lot of things this week – how to shoot, how a distributor works on a truck, that sugar in your coffee makes your babies be born naked and that nice people have nice parents. ☺

Dear Mr. and Mrs. Hensley,
Thank you for letting me come visit this week. I really enjoyed getting to know you. Thanks for making me feel like I belonged. I learned a lot of things this week – how to shoot, how a distributor works on a truck, that sugar in your coffee makes your babies be born naked and that nice people have nice parents. 😊*.*

July 1985

I could see that she loved nature, but I was also learning how much she loved other people. In a letter to Adele, I told her that a little girl named Karissa, whom Adele had met during her Spring Break visit, had been seriously hurt in a tricycle accident. At the time, Adele was working as a day camp counselor at the YMCA in Baton Rouge. She was supervising a group of 7- and 8-year-old girls that week. And so, Adele marshalled her troops:



You should be getting a brown envelope soon but the contents aren't really for you, they're for Karissa, My girls sent her

2

some cards to help her feel better.

You should be getting a brown envelope soon but the contents aren't really for you. They're for Karissa. My girls sent her some cards to help her feel better.

December 1985

At first, I was a Computer Science major and Adele was a pre-med Biology major. But we both changed our minds. I quit Computer Science after one semester because my first programming class was boring and because I really wanted to work with animals. Adele's change was slower and harder.

> *Dear Frank,*
> [6 pages of other stuff…]
> *I have been tossing things around in my head – thanks for the prayers – and I think I've got some answers, and I don't have any idea how I'm going to tell my mother and father and everybody else. But I will . . . I said, "Adele, what do you want? What do you want to do with the rest of your life? And are you going to be happy, or is happiness what you're looking for?"*
>
> *For a long time now, more than just one or two years, I've been trying to come up with a good answer to why I wanted to be a doctor and I think I didn't try very hard because I was afraid of what I might learn about myself. It has often been one of my greatest failings that much of what I do is done on an instinctive basis rather than a rational examining one. In the 11th grade I thought it would be fun to be a biologist, but I guess it*

> *seemed easier and much more practical to study medicine… Remember when Marla and Dale*[6] *decided medicine wasn't for them? That really scared me. I thought, "What if I change my mind, too? What would I do?" They seemed so sure… and they've changed their minds – what am I going to do?*
>
> *…It would be exciting to be a doctor – to be so trusted that people would ask you to help them to feel better – but I'd rather be trusted for who I am than for what I do. And you were right – I'd rather have long-term dealings with people and get to know them and be their friend than to be some mysterious figure seen only five times in as many years. A long time ago I decided that if I were a doctor I would spend a lot of time helping people to understand that most of their illnesses come from their heads – not that they were imagining themselves to be ill but that because they didn't feel happy or content or un-pressured they didn't feel good – and maybe if they could figure out what was bothering their minds they (or we) could stop what was bothering their bodies. But I'm wondering if there's another way I could do this – Isn't there a better reason for going into medicine than to try not to use it?* 😆
>
> *What I like to do best in the area of helping folks feel better is to listen to them as much as they need me to and I often feel very frustrated because I can't give them any answers, but I'm finally learning that other people can't always give you answers – sometimes a person just needs someone to listen so maybe he can work it out himself. And it's probably necessary to let people solve their problems themselves and maybe just be there if they need to discuss it. Really, I don't see medicine or being a doctor as a good means of establishing the long-term friendships and relationships that I'd like to have and that would allow what I just described.*

By the time she was ready to let go of medicine, I was encouraging her to become a biologist. I was in the process of switching my own thinking from being a game warden or a wildlife biologist with a government agency to

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[6] Two dear friends at Baylor

becoming a professor, and Adele was swept along in that current. So that's the direction we headed together.

Summer and Fall 1986

I had saved money all summer, working a job I hated but couldn't quit because Dad had talked one of his fishing buddies into hiring me, and because Adele needed an engagement ring. But she didn't. Adele didn't want a ring – she just wanted me. She liked jewelry best if it was hand-made by her Grandpa Jack or depicted animals (which most of his pieces did). But sparkle wasn't all that special to Adele. Nevertheless, I chose a diamond mounted on a plain gold band, priced at the upper end of what I could afford, and paid for by the sweat of my brow (which mattered to me – I declined a family diamond that was offered). None of that mattered to Adele.

I brought the ring to Waco, but she was expecting it and I wanted to surprise her, so I waited a couple of days and didn't propose while my parents were with us, which she later told me confused her. One evening after supper with Kurt and his wife Marla, Adele and I went for a walk around campus. Classes weren't in session and the academic buildings were deserted and dark. We made our way up the steps of the library, where we had studied together for hundreds of hours by that time, and we sat on a heavy concrete bench. [I just did a Google search, and yes, there's that bench!]

I don't remember the words I said. My heart was pounding. I asked her to marry me, but I didn't wait for an answer; I took her hand, not unlike the Jell-O incident, and slipped the ring on her finger. She kissed me before she said yes, then kissed me again. She didn't look at the ring. She didn't squeal or jump up. She just hugged me and held me and kissed me and said yes again. She was tender, and serene. And then, when the moment was over, she said, "Can you feel how fast your heart is beating??!!"

November 1986

At Baylor people made a big deal about Homecoming, including getting dressed up in suits and dresses to go to the football game. But Adele had to march with the band and play trombone, and I'm no football fan, so we usually didn't make a fuss. Our senior year, however, we decided that after the ball game we would get dressed up and go eat steaks at Lone Star Tavern (Not the large chain of steakhouses that is popular today, but a locally owned place in Bellmead with incredible food. If you know, you know!).

Adele with her friend Mike from the trombone section.

At the time I was enrolled in my first ever graduate-level class, Ecological Genetics. For my class project I was studying whether roads were barriers to gene flow. I had already sampled snails on both sides of a road that I had chosen, but I needed to look for actual gene flow, snails moving across the road. Well, while we were eating steaks, down came the rain. When we had finished, I looked across at Adele, all made up and wearing a dress, and I said, "I need snails for my project for Dr. Pierce's class." And without hesitating she said, "Let's go!" So, 30 minutes later we were outside of Woodway and there she was, in the glow of the headlights, in a cream-colored linen dress with a straight skirt, and her highest (pretty low) heels, picking snails off the shiny wet asphalt. We had been engaged for about three months, but if I still had any lingering doubts that she was the girl for me, that dispelled them!

Spring 1987

I do dishes. I mean everyone does, but among household tasks, I prefer it to everything but folding laundry. Folding laundry lets me be productive while sitting and watching *Star Trek* or *Firefly.* But doing dishes is noisy and wet and you must stand up, so it isn't really TV time.

Adele was an excellent cook, with a creative streak, and sharing delicious food with others made her feel like she was nurturing and sharing and building community with friends and family. It helped her establish the kind of connections she thought she'd never have as a doctor. To me, cooking is just hard work. But I love good food. So, in college Adele and I fell into a pattern. Once we had off-campus apartments we often ate together, sometimes at her place and sometimes at mine. But Adele took the lead on [that means, "did everything"] cooking and once we had eaten, I did the dishes.

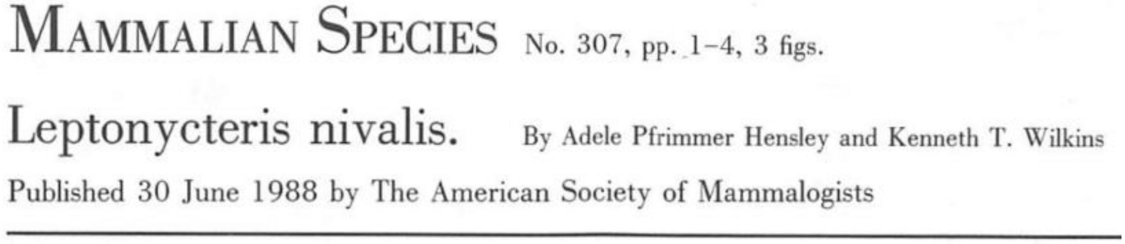
Supper at Adele's apartment often included her dear roommate Sharon. Poor Sharon. You see, our kitchen conversations were not palatable for most people. Sharon coined what I called Sharon's Law: "Never eat with a biologist." Each supper was likely to include whatever we had studied that day – turtle heart physiology, rodent urine, snake genitalia… there was no topic that could ruin a good plate of spaghetti (for two of us, anyway).

In the Fall of 1986, we were officially a one-dream team. We needed to finish our Honors Theses in biology and get accepted to a preferred doctoral program! One key step was the Graduate Record Exam (GRE). We didn't give the regular GRE much thought because we focused on the GRE Biology exam. Nobody takes that exam anymore, but for us it was going to be our ticket to the

Ph.D. programs we longed for. So, we had to study. And we were already an exceptionally effective study team (except for calculus). Adele cooked while I read questions to her from the prep manual. We would deliberate, choose our answers, and then I'd check the answer key in the back of the book. After we ate, I dished, while she dished out questions. We did this five or six nights a week for about two months, in addition to diligently studying for our regular classes.

We were both accepted to all four graduate schools we had applied to, with offers of tuition waivers and assistantships. Adele scored a few % above me on the GRE, so she was invited to visit the University of Florida, at their expense, because she was a top candidate for a graduate fellowship (her academically inferior fiancé was told to pay his own way, so he didn't travel with her). Adele was awarded the University of Florida's Presidential Fellowship, their most elite package of support for incoming graduate students. Her three-year stipend was about 50% higher than I was paid, so when I bragged about her, I also told everyone I was marrying her for her money!

I did well at Baylor, but Adele did better. She wrote her Honors Thesis on the pollination of a native species of Dayflower, earning the designation Honors Program with Distinction. She was elected to Phi Beta Kappa and was recognized as the Outstanding Senior Woman in Biology. She also published her first scientific paper, about a bat that pollinates flowers, with one of her favorite professors. Because both of our families would be travelling from out of state to attend our graduation, we decided to be efficient; we graduated from Baylor on a Friday and got married the next day. Bachelor's degrees in hand, we moved to Gainesville, Florida and entered the Ph.D. program in Zoology at UF.



MAMMALIAN SPECIES No. 307, pp. 1–4, 3 figs.

Leptonycteris nivalis. By Adele Pfrimmer Hensley and Kenneth T. Wilkins

Published 30 June 1988 by The American Society of Mammalogists

II. Grad School

1987-1991

Those evenings studying for the GRE in our kitchens had cemented us together more deeply. Sticky dough, sticky rice, and sticky hearts. When we got to UF, we had plenty of studying to do, but the kitchen had become both domestic and a bit sacred … and so science was ushered out. After all, we had an office to work in now. Instead, we began reading fiction to each other in the kitchen. And we learned that some popular fiction just doesn't read aloud very easily – we stumbled over even familiar words, and grammatically correct sentences offered up by some accomplished authors could still trip us up with an awkward rhythm. But we also found some things that seemed like they were written for recitation. They flowed so easily. Early in graduate school we tackled *The Lord of the Rings*, and it was in Middle Earth that Adele discovered that she'd married a Philistine (well maybe I should say an orc.) She had read the trilogy once before and I had read it three or four times. But I had to confess to her that in my previous readings I had mostly skipped over the poetry. [No, not all of it! I did know by heart, "*Three rings for the elven kings…*" but most of the longer verse I had never read. If I didn't think it advanced the plot, I wasn't motivated.] This time through, we read it all. But sometimes, while she was cooking, I'd come up to some of Tolkien's long verses, and I'd offer to stir the pot while she handled the stirring words. She could sight-read the poetry fluidly when I might stumble, and she could even improvise a tune when the verse was actually sung in the story.

In the years B.C. (Before Clark) we read many hours to each other. But Adele would cheat. I'd come home and find our shared book face down, open to a spot 50 pages ahead of where we'd left off the evening before. I chided her for it, but she was a voracious reader, hungry for words whether they were narrative or quatrains echoing with the clash of shields and spears; she just couldn't put a book down. And so, I acquiesced. If she was reading to me, and came to a surprising plot twist, she'd do her best to sound genuinely surprised, but sometimes her tone betrayed her, and I knew she had read ahead. She wanted to share the adventure with me, but she also wanted to keep reading when I wasn't around to listen!

Reading together eventually fell by the wayside, as the busyness of life and our teaching and research took over, until Harry Potter. Adele heard about it, bought it, and devoured it. Then she brought it to me and said, "We need to read this together." Of course, I said something to the effect of "…and you know this because you've already read it." Adele was often frustrated that she would recommend books to me that I'd never even try. I had fallen out of the habit of reading much for pleasure, and wouldn't find time for it until nearly bedtime, at which point only a couple of pages would put me to sleep. But Adele insisted I listen to her read me the first few pages of Harry Potter, and of course I was hooked. I think we ended up reading the first three or four together when they were new, and eventually reading the first couple to Clark before he began reading them on his own. Bringing Clark into our reading, and then having him grow out if it, was seamless on both ends. Sadly, as reading to Clark waned, reading as a couple did not come back. We let the internet and television occupy that space in our lives, forgetting what a good bonding agent crisp, dry pages can be. And that is the first regretful thought I've had as I write to celebrate our adventures in Middle Earth and at Hogwarts.

We laid down some great memories in Florida, floating in inner tubes on the Ichetuknee River, canoeing the Silver River, and mountain biking at the Lower Suwanee National Wildlife Refuge where a family of five river otters ran across the trail in front of us, each one stopping in turn to give us a hard look. We studied with world-class scientists, helped collect blood from alligators and injected Argentine horned frogs with hormones to get them to breed so we could study tadpole feeding behavior. Adele worked on lizard reproduction, sorted zoological specimens from paleolithic human settlements, and became a "rat madame" as she bred dozens of rats for her thesis research.

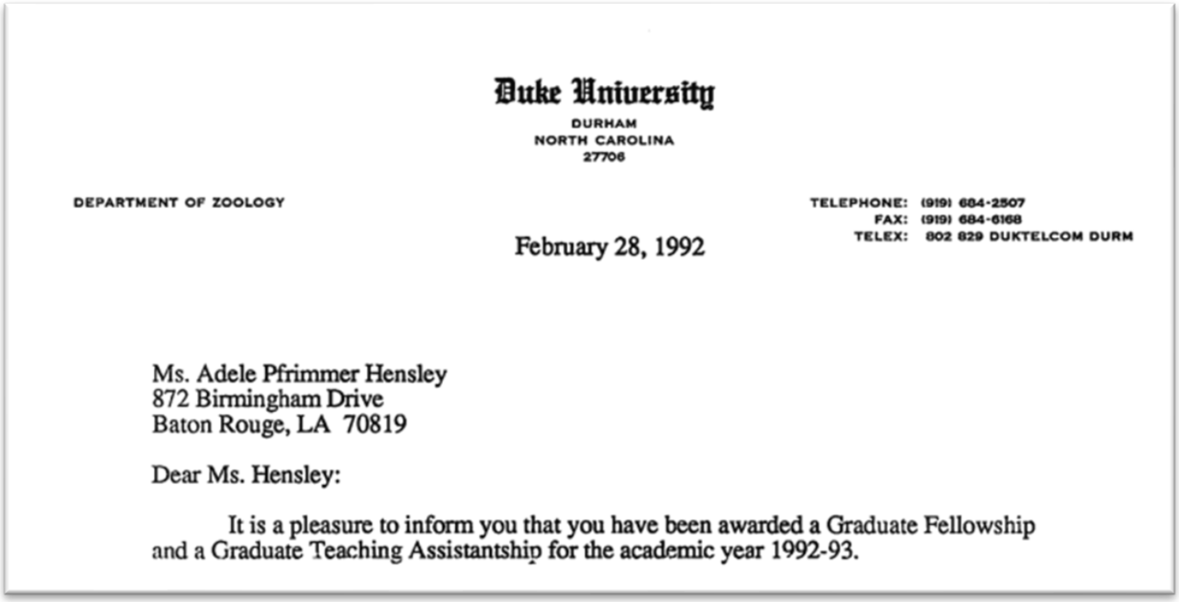
On rainy nights we were out on the roads again, not looking for snails this time, but chasing randy frogs for my thesis research and always on the lookout for snakes. I had fallen in love with snakes as a child, first when I checked out a library book about amphibians and reptiles, and then when my parents built a house on a riverbank where I caught my first snakes as a second grader. Adele was just starting to get to know them. Of all the fun activities we did, none was more frequent than "road cruising" for snakes down Highway 441 across Paynes Prairie to the ominously-named River Styx. She'd sit in the middle of the bench seat of my Ford F-100 pickup and snuggle up close to me and sing along with the radio while I drove along dark rural roads at 15 miles per hour, hoping to see a snake. Back then we'd listen to country music, and one of my favorite groups was Alabama… the soundtrack for road cruising with Adele, in my mind, includes the song Dixieland Delight:

Rollin' down a Backwoods, Tennessee byway
One arm on the wheel
Holdin' my lover with the other
A sweet, soft, southern thrill
Worked hard all week, got a little jingle
On a Tennessee Saturday night
Couldn't feel better, I'm together
With my Dixieland delight

Adele completed her M.S. in Zoology in 1991, working on how plant-produced chemicals that mimic estrogen can affect the reproduction of mammals. She wanted to continue in the Ph.D. program, but her research interests necessitated a move. I was already headed to the Savannah River Ecology Lab (SREL) in South Carolina for a Ph.D. fellowship, so after a year with me in South Carolina, where she taught Biology for two small colleges, Adele headed off for North Carolina…

In 1989 I had the opportunity to spend seven weeks in Costa Rica working on the endangered Golden Toad. Golden Toads are almost certainly extinct now due to a fungal disease that swept south through Central America in the late 1980's, and I have the dubious distinction of being the last person to ever see one. Those seven weeks were really hard, and I missed our second wedding anniversary, but it confirmed what we knew in our hearts; separation for long periods was no fun, but it was no threat to our relationship. We spent the summer of 1990 apart when I went to SREL for the first part of my fellowship. Then in August of 1992 we started a 16-month stretch of living in two different states. People asked me if we fought about these decisions to be apart. During these long separations various people asked if we worried that we'd grow apart or find someone else. I was dumbfounded by these questions; it seemed to me that if a couple's relationship wasn't solid enough to endure it, they'd know not to enter into such a period apart.

1992-1993



Duke University
DURHAM
NORTH CAROLINA
27706

DEPARTMENT OF ZOOLOGY

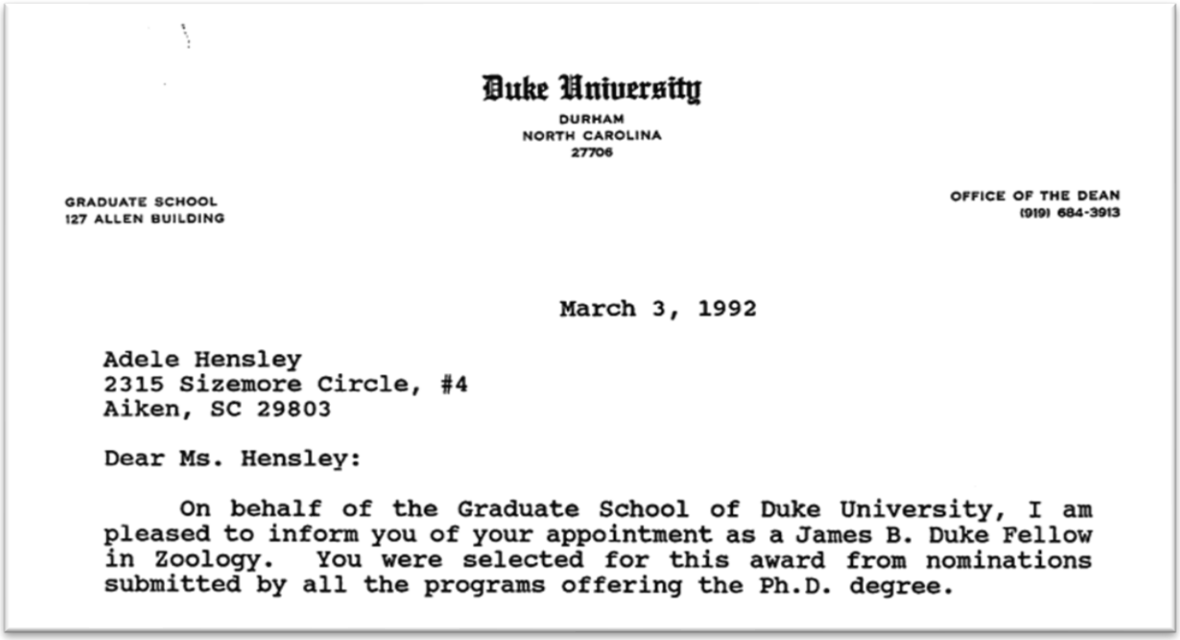
TELEPHONE: (919) 684-2507
FAX: (919) 684-6168
TELEX: 802 829 DUKTELCOM DURM

February 28, 1992

Ms. Adele Pfrimmer Hensley
872 Birmingham Drive
Baton Rouge, LA 70819

Dear Ms. Hensley:

It is a pleasure to inform you that you have been awarded a Graduate Fellowship and a Graduate Teaching Assistantship for the academic year 1992-93.



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GRADUATE SCHOOL
127 ALLEN BUILDING

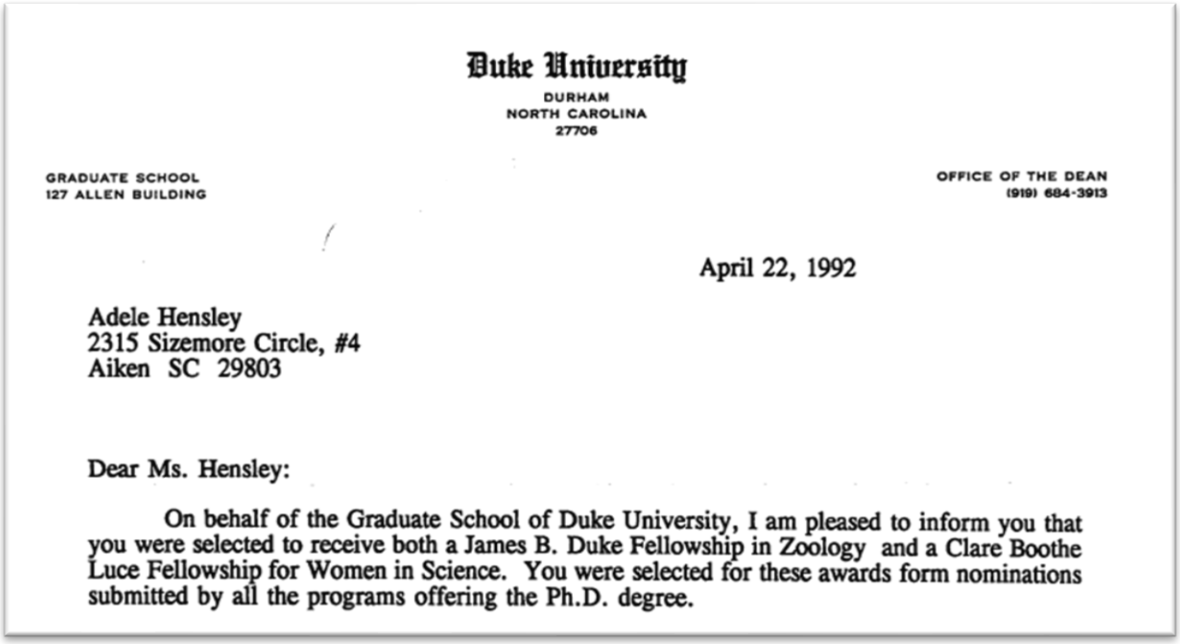
OFFICE OF THE DEAN
(919) 684-3913

March 3, 1992

Adele Hensley
2315 Sizemore Circle, #4
Aiken, SC 29803

Dear Ms. Hensley:

On behalf of the Graduate School of Duke University, I am pleased to inform you of your appointment as a James B. Duke Fellow in Zoology. You were selected for this award from nominations submitted by all the programs offering the Ph.D. degree.



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(919) 684-3913

April 22, 1992

Adele Hensley
2315 Sizemore Circle, #4
Aiken SC 29803

Dear Ms. Hensley:

On behalf of the Graduate School of Duke University, I am pleased to inform you that you were selected to receive both a James B. Duke Fellowship in Zoology and a Clare Boothe Luce Fellowship for Women in Science. You were selected for these awards form nominations submitted by all the programs offering the Ph.D. degree.

Adele and I missed each other terribly for the 16 months we were apart. We only managed visits every three or four weeks, and once had to wait seven weeks without seeing each other. We were miserable about it but resigned to the fact that we'd chosen this to advance our educational goals. I immersed myself in my science, knowing that the sooner I finished data collection the sooner I'd be able to live with Adele again. Adele, on the other hand, found our separation very counterproductive, and she struggled with three difficult mathematics-based classes, with anxiety about whether she was capable of doing the science, and with just being lonely for me.

> *Date: Tue, 20 Apr 93 12:15:12 EDT*
> *From: ah@mendel.zoo.duke.edu (Adele Hensley)*
> *To: hensley@srel.edu*
>
> *dear frank,*
>
> *i love you.*
>
> *i don't think i'm getting this project done right. i feel terrible about it, too.*
>
> *i love you a ton. you are the greatest.*
> *i will probably talk to you tonight.*
>
> *gotta go work.*
>
> *delly*

It wasn't all misery. Adele found a church she really liked and there she made some of the longest and dearest friendships of her life.

Until she got to Duke, Adele had almost always made A's in her classes. But in each of her first three semesters at Duke, she earned an Incomplete in one class, two of which became her permanent grade. She made A's in her other classes, but these three were demoralizing seeds of self-doubt. Adele had always been confident, so this change was unexpected. She attributed it to missing me; it never occurred to us that anything else could be going on.

1994-1998

One of Adele's greatest loves was singing. And during her sojourn at Duke, when graduate school was so hard and often discouraging, music was one reliable source of comfort and joy. In North Carolina she first experienced Sacred Harp music, which is sung *a capella*, in large groups, with the four vocal parts seated in a square facing each other. Singers take turns leading the group from the middle of the square. The thing that stood out to me when I attended a "sing" with her was that singing Sacred Harp does not necessarily require a great singing voice, but it is not for introverts. Every song is energetic (I'm being coy here; I mean LOUD. They belt it out!).

> *Date: Mon, 3 May 93 11:16:39 EDT*
> *From: ah@mendel.zoo.duke.edu (Adele Hensley)*
> *To: hensley@srel.edu*
> *Subject: monday*
>
> *dear frank,*
>
> *i love you a ton.*
> [...]
> *i can't get the sacred harp songs out of my mind. it was really really fun yesterday--i'd even say thrilling for one of the songs i led. there's nothing quite like standing in front of all that loud sound on a beautiful song.*
>
> *i love you more and more every day.*
>
> *your bear*[7]*,*
>
> *delly*

---

[7] Like any couple, Adele and I had pet names we used for each other. Her use of "bear" was part of how we talked to each other then. I think it eventually became infrequent, as other nicknames came into use. Perhaps Clark heard us call each other "bear" occasionally; perhaps not. Adele's family frequently call her Delly.

In addition to singing Sacred Harp, Adele became a member of a highly regarded local vocal group called The Solstice Assembly[8]. They would fill large auditoriums a couple of times per year, and even had a patron that paid all expenses for the group and their families to travel to Myrtle Beach, South Carolina for a weekend to put on a concert. The leadership of The Solstice Assembly disbanded the group about a year after Adele joined, and several singers from that group then became part of another strong local folk group called Night Air.

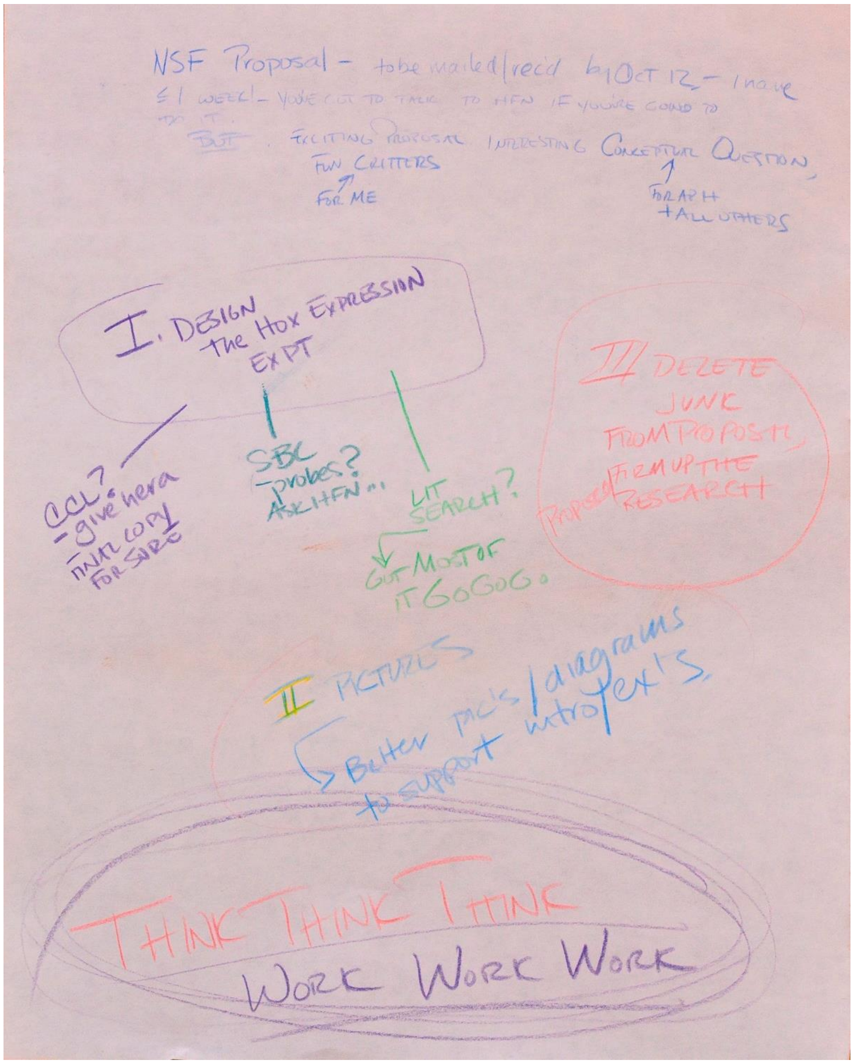
With Night Air, Adele sang in holiday concerts and fundraisers for Charles House, an adult daycare center. In the early years of our marriage, she was always singing when she wasn't doing science (and sometimes when she was). She would sing when I brought her a cup of coffee in the morning and sing on-and-off all day. If she was reading or studying, she'd be silent, but any activity that could use a soundtrack got one! Folk tunes and choral material dominated her repertoire, but she sang hymns, children's songs, pop, country, and rock and roll, too. She sang every single day and even let me join in – a most loving gesture considering what kind of singer I am.

In December of 1993 I was able to move to North Carolina. What a relief! We were together again! Time to rent a little house and get a dog! Or two!

---

[8] A couple Solstice Assembly albums are available for purchase on the internet, but these were recorded before Adele joined the group.

My arrival in NC gave Adele a new focus on her doctoral research…



NSF Proposal – to be mailed/rec'd by Oct 12 – I have
≤ 1 WEEK! – YOU'VE GOT TO TALK TO HFN IF YOU'RE GOING TO DO IT.
BUT. EXCITING PROPOSAL INTERESTING CONCEPTUAL QUESTION,
FUN CRITTERS
FOR ME
FOR APH
+ALL OTHERS

I. DESIGN the Hox EXPRESSION EXPT
CCL? – give hera final copy for sure
SBC – probes? ASK HFN…
LIT SEARCH?
GOT MOST OF IT GO GO GO.

II PICTURES
Better pic's/diagrams to support intro/ex's.

III DELETE JUNK FROM PROPOSAL, FIRM UP THE Proposed RESEARCH

THINK THINK THINK
WORK WORK WORK

NSF Proposal – to be mailed/rec'd by Oct 12 – I have ≤ 1 week! You've got to talk to HFN[9] if you're going to do it. But… Exciting proposal (fun critters ←for me) Interesting conceptual question (←for APH + all others).

- I. *Design the Hox expression experiment (CCL – give hera final copy for sure)(SBC probes? Ask HFN…) (Lit Search – got most of it – go go go).*
- II. *Better pics/diagrams to support intro ex's.*
- III. *Delete junk from proposal. Firm up the proposed research. <u>THINK THINK THINK WORK WORK WORK</u>.*

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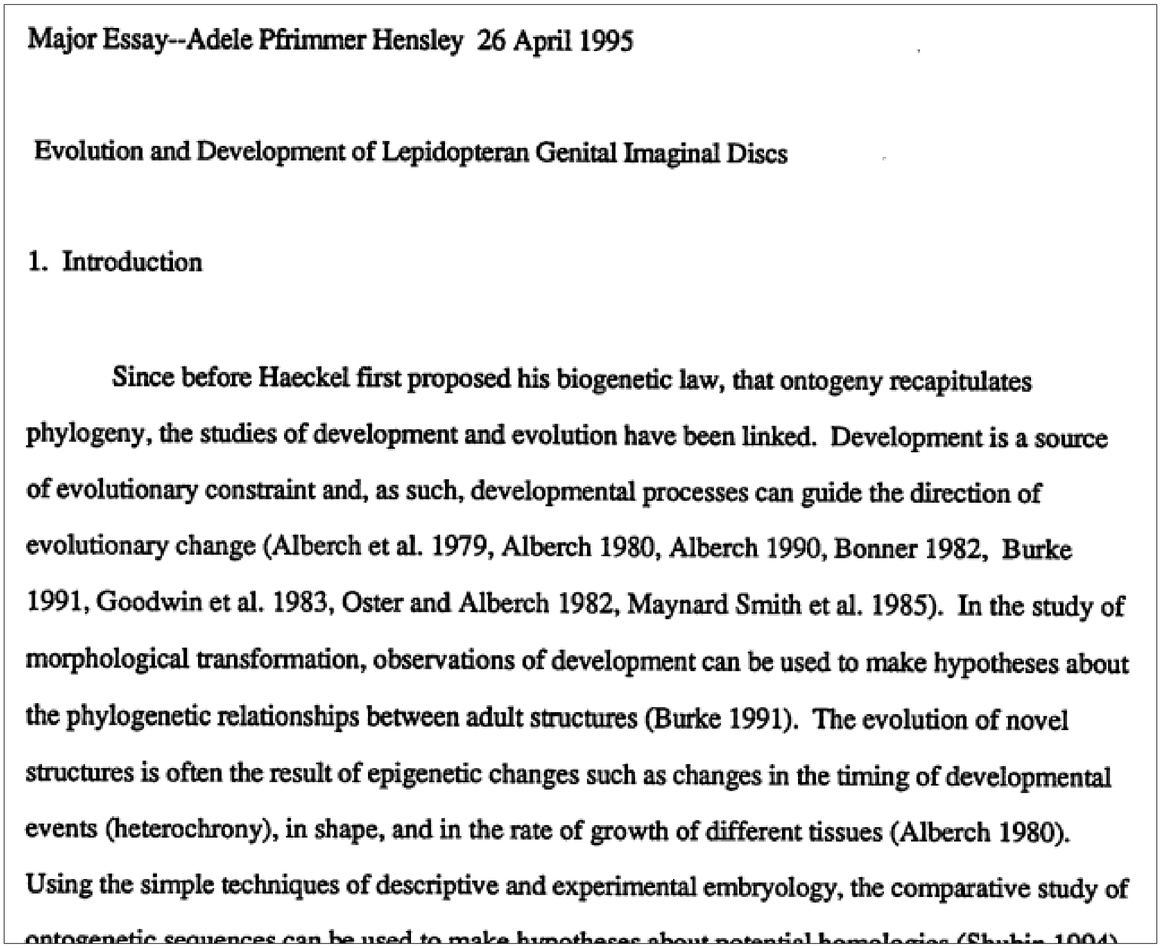
[9] Dr. H. Frederick Nijhout was Adele's major professor at Duke. I'm not sure what much of the jargon means.



Major Essay--Adele Pfrimmer Hensley 26 April 1995

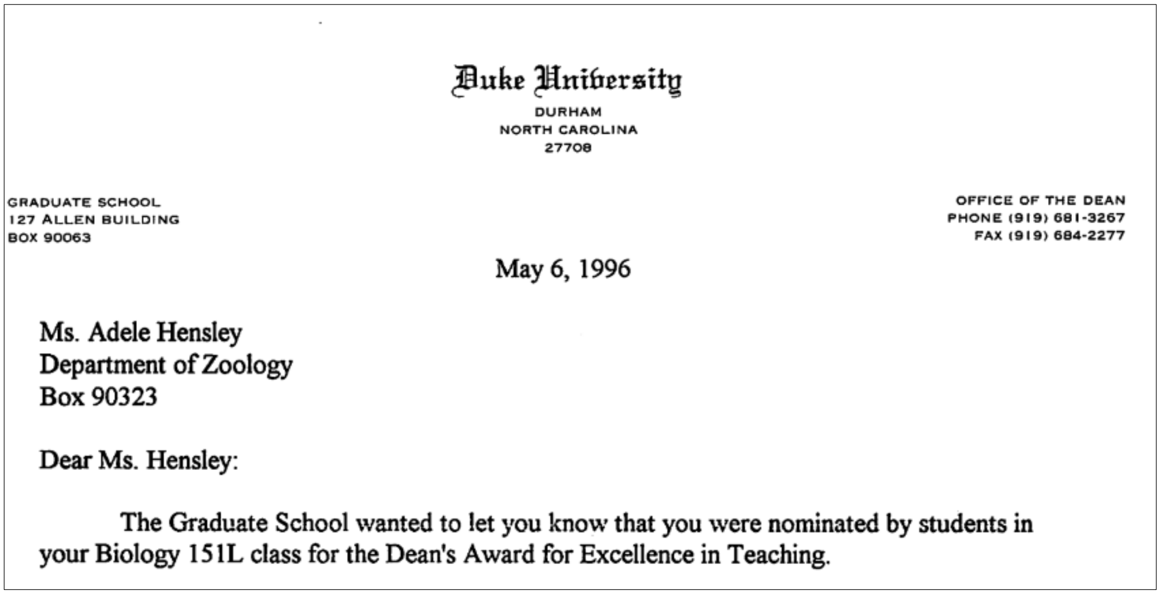
Evolution and Development of Lepidopteran Genital Imaginal Discs

1. Introduction

Since before Haeckel first proposed his biogenetic law, that ontogeny recapitulates phylogeny, the studies of development and evolution have been linked. Development is a source of evolutionary constraint and, as such, developmental processes can guide the direction of evolutionary change (Alberch et al. 1979, Alberch 1980, Alberch 1990, Bonner 1982, Burke 1991, Goodwin et al. 1983, Oster and Alberch 1982, Maynard Smith et al. 1985). In the study of morphological transformation, observations of development can be used to make hypotheses about the phylogenetic relationships between adult structures (Burke 1991). The evolution of novel structures is often the result of epigenetic changes such as changes in the timing of developmental events (heterochrony), in shape, and in the rate of growth of different tissues (Alberch 1980). Using the simple techniques of descriptive and experimental embryology, the comparative study of ontogenetic sequences can be used to make hypotheses about potential homologies (Shubin 1994)

In 1995 Adele submitted her “Major Essay” to her doctoral committee. This was her proposal for her dissertation research. She had an oral exam on this, and her supervisory committee approved the project unanimously. One committee member said that every couple of years he would read a research proposal that would make him want to abandon his own research agenda and switch to whatever that remarkable proposal was about. He said Adele’s proposal did that for him! She felt such a huge sense of relief and accomplishment. (I had a personal victory, too. The night before she distributed the document to her committee, she stayed up all night writing and revising. I sat up with her all night long. I had never “pulled an all-nighter” for any academic effort before, and I was a groggy mess after about 1:00 AM, but I did stay awake and encourage her, even if my ability to critique and edit was severely compromised.)

In addition to excellent research progress, she was doing a fantastic job with her teaching, too.



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OFFICE OF THE DEAN
PHONE (919) 681-3267
FAX (919) 684-2277

May 6, 1996

Ms. Adele Hensley
Department of Zoology
Box 90323

Dear Ms. Hensley:

The Graduate School wanted to let you know that you were nominated by students in your Biology 151L class for the Dean's Award for Excellence in Teaching.

My Ph.D. was finished, and she was on track to get hers. All was right in the world!

******

But it wasn't. And we didn't know why. We didn't know, couldn't know, that an insidious assault had begun. Soon Adele was really struggling to make progress on her dissertation project, even though her committee had been very satisfied with her proposal. Her difficulties turned to self-doubt, and she began questioning whether the Ph.D. was the right path for her. In times of stress and doubt, Adele had always found comfort in prayer and at church, but now church was just making her feel worse.

Diaconate of Watts Street Baptist Church
800 Watts Street
Durham, North Carolina 27701

Dear Rhonda and Dennis,

Please accept this as my resignation from the diaconate of Watts Street Baptist Church. I think that this caring ministry is important to the life of our church, but I also think that I have not lived up to the pastoral care ideal we have set for WSBC deacons.

This has been a difficult couple of years for me personally, professionally, and spiritually. I am not sure which of these things have been the causes and which the effects, but I do know that if I want to be able to finish my degree, I need to devote most of my energy right now to my schoolwork. To do this, I also need to be able to worship freely in our church. Unfortunately, I have been feeling so guilty every time we have a confession, a prayer, or a communion service, that I had almost quit coming to church. Ever since I talked to Mel about resigning and decided to quit being a deacon, I feel much more at peace. I do not know if this is the sort of ministry that I will never be suited for, or if it is something I could do at a different time of my life. I just know that I cannot do it right now.

Sincerely yours,
Adele Pfrimmer Hensley

It would be over a decade before we began to recognize that Adele's struggles with what to do with her life were, probably to some degree, the first signs of declining executive function, a symptom of Parkinson's disease. Nobody can use indecisiveness to diagnose Parkinson's disease, but the declining production of dopamine in the brain means that deferred rewards are hard to choose when more immediate rewards are available. Adele was a patient person, at least with children and her husband. But Adele was also a spontaneous, even impulsive person, about some things. And it's very hard to commit to the long haul of scientific research if it isn't generating frequent dopamine rewards in your brain. Especially when you're getting that dopamine from loving people by teaching them, leading them in song, meeting for coffee, and every activity besides sitting in the lab dissecting caterpillars.

Adele thought that part of her problem was a writing problem as much as anything else, so she started working directly on writing.

12/12/95 *This notebook is my writing practice notebook. I will use it to practice expository writing. This will be the place where my writing can 'sleep' so that I can look at it and revise it with a fresh eye…*

I need to make a list of topics I need to write about

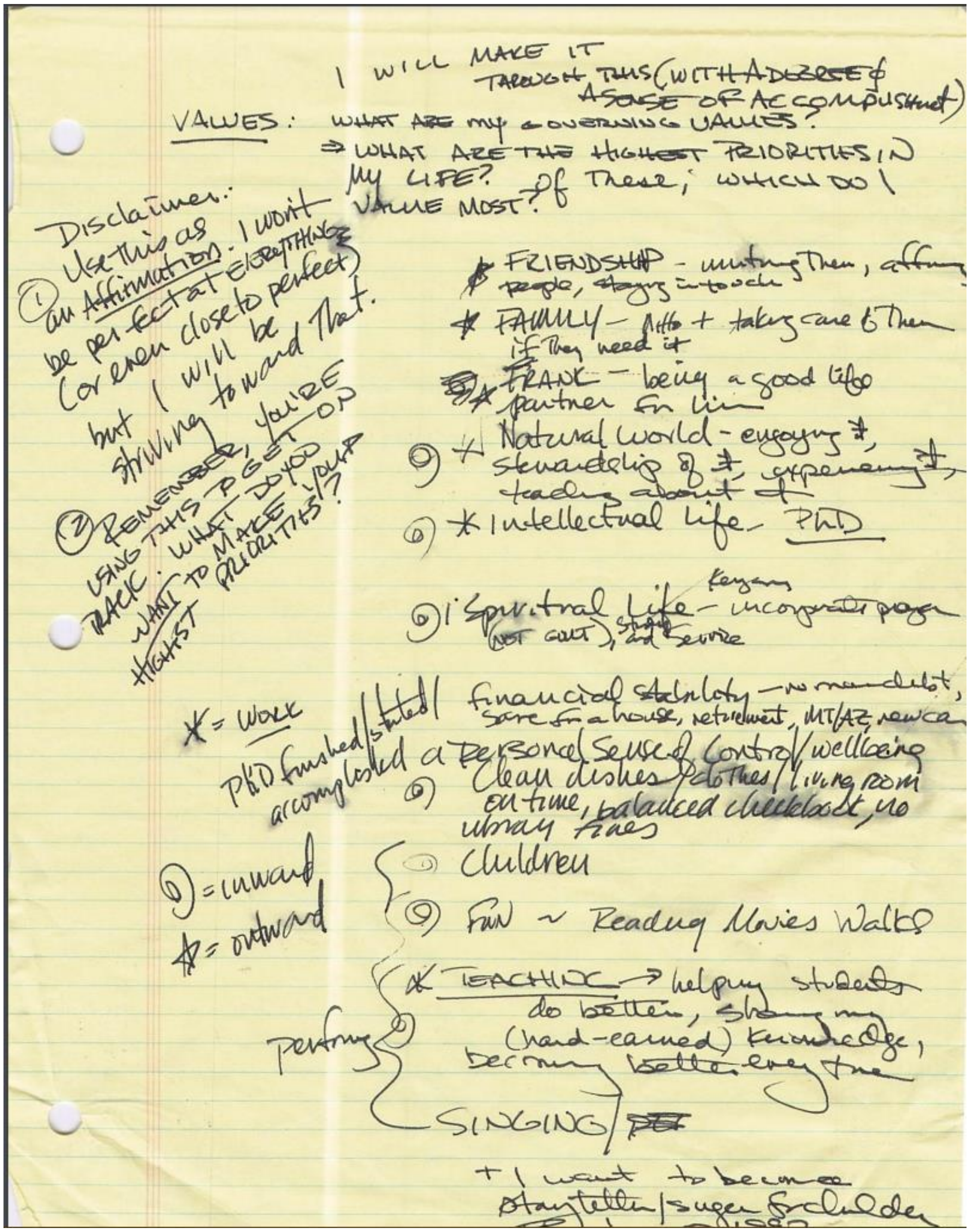
1. *A teaching philosophy*
2. *Explain your research topic in one minute, 5 minutes, twenty minutes*
3. *Describe development of GIDS*[10]
4. *Explain what a GID is*
5. *Explain why it would matter if differentiation is not strictly separated, in time, from cell division*
6. *Explain what a hormone is*
7. *Explain the check mechanism in insect wings*
8. *Explain homeotic genes – function and evolution*
9. *Describe what you see when you look in a caterpillar, an imaginal disk*
10. *Explain exactly what's going on with the sliding filament model and excitation contraction coupling*
11. *Why are you training to be a scientist? This kind of scientist?*
12. *What are the important implications of your work?*
13. *Writing a one-page treatment of a course you would enjoy developing*
14. *Develop new labs for an entomology course*
15. *Write out a detailed protocol for caterpillar rearing/care*

Adele began keeping personal journals and seeing a counselor to help her cope with anxiety about her career. Over the course of her early adult life, Adele started keeping journals several times, but she generally quit after just a handful of entries. However, in 1996-98, she wrote in her journals regularly. I

---

[10] GID means genital imaginal disk, a cluster of undifferentiated stem cells in a caterpillar that develops during the chrysalis or pupa stage into the reproductive structures in an adult butterfly or moth.

never read any of it until 2023, and I'll only share just a few droplets here, since she never meant for anyone else to read it. But a little bit gives some insight into her struggles. (I have transcribed it below, so you can skip struggling with her handwriting).



I WILL MAKE IT THROUGH THIS (WITH ~~A DEGREE~~ & A SENSE OF ACCOMPLISHMENT)

VALUES: WHAT ARE my GOVERNING VALUES?
⇒ WHAT ARE THE HIGHEST PRIORITIES IN MY LIFE? Of these, which do I VALUE MOST?

Disclaimer:
① Use this as an Affirmation. I won't be perfect at EVERYTHING (or even close to perfect) but I will be striving toward that.
② REMEMBER, YOU'RE USING THIS PG TO GET BACK ON TRACK. WHAT DO YOU WANT TO MAKE YOUR HIGHEST PRIORITIES?

* FRIENDSHIP - nurturing them, affirming people, staying in touch
* FAMILY - ditto + taking care of them if they need it
* FRANK - being a good life partner for him
⊙ * Natural world - enjoying it, stewardship of it, experiencing it, teaching about it
⊙ * Intellectual life - PhD
⊙ I Spiritual Life - incorporate prayer (NOT GUILT), Kenyan study, and service
financial stability - no more debt, save for a house, retirement, MT/AZ, new car
PhD finished/started accomplished a Personal sense of control/wellbeing
⊙ Clean dishes & clothes / living room on time, balanced checkbook, no library fines

* = WORK

⊙ = inward
* = outward

⊙ Children
⊙ Fun ~ Reading Movies Walks
* TEACHING → helping students do better, sharing my (hard-earned) knowledge, becoming better every time
performing ⊙ SINGING / ~~[illegible]~~

+ I want to become storyteller/singer for children

I WILL MAKE IT THROUGH THIS (WITH A DEGREE & A SENSE OF ACCOMPLISHMENT)

VALUES:
What are my governing values?
What are the highest priorities in my life?
Of these, which do I value most?

Disclaimer:

1) Use this as an affirmation. I won't be perfect at everything (or even close to perfect) but I will be striving toward that
2) Remember, you're using this to get on track. What do you want to make your highest priorities?

✸Work: PhD finished/started/accomplished
@ inward
★outward

★Friendship: writing them, affirming people, staying in touch
★Family: ditto + taking care of them if they need it
★Frank: being a good life partner for him
@✸Natural World: enjoying it, stewardship of it, experiencing it, teaching about it
@✸Intellectual life: PhD
@Spiritual life: incorporate prayer (not guilt) keeping steady and serene
Financial stability: no more debt, save for a house, retirement, MT/AZ, new car,
@ a personal sense of control/wellbeing:
clean dishes/clothes/living room on time, balanced checkbook, no library fines
@ children
@ fun: reading, movies, walks

★performing:
Teaching – helping students do better, sharing my (hard-earned knowledge, becoming better every time
Singing – I want to become a storyteller/singer for children

I was surprised in 2023 to read that Arizona was on her retirement list. She loved Montana, the ancestral home of her father's family, so that was an obvious place to dream of retiring. But I don't know why she had Arizona on her list in 1996… neither of us had ever been there, and it would be two more years before I applied for a job there. Actually, I do know why. As nature lovers, we dreamed of far-off lands with exotic fauna – Australia, the Galapagos, and the Arizona desert were environments we hoped to see one day.

28 July 1996

This weekend I thought really hard about why I'm spending so little time working. I know part of it is that once (if) I start it will be all-consuming from here on out. I think I'm afraid of that. Another problem is that I have no idea where to begin, and I feel guilty for having accomplished so little. I'm in the same place I've been before: at loose ends, no idea what to do first, or next, or today. I've decided that maybe my problem is I'm good at some things, but not at research. I think I'm a good teacher. I like students, I like helping them. I like looking things up and facilitating things. I don't like being isolated and I'm not good at being self-directed. Give me a task, I'll do it, BUT I DON'T KNOW THE FIRST THING TO DO! So last night driving back home from a collecting trip to Virginia, I decided that maybe I should quit (But what would I do? I could teach school?) I talked to Frank this morning. He said 1) getting the degree does not mean I have to do this my whole life and 2) be happy.

I called Cathy Cox, teacher, turned biology PhD. She let me cry and tried to get me to state some specifics of what I have done and need to do. She said that she cried every night for six months when she was working hard on her research, until six months before the end when she was sure she'd finish. She said, "Adele you're so much like me you want to be perfect. You just need to be good enough." She told me to make a list of IMPOSSIBLE, SORT OF HARD, DOABLE BUT TIME CONSUMING, NEED HELP stuff and do something every single day. I'm going to do that now. I feel tired/exhausted and worried. But talking to Cathy really calmed me. Thank God I found her today and fast.

I don't recall much about that conversation that Sunday morning. Except the two things she listed as my response to her have stuck with me ever since. First, what I said about how she could finish the Ph.D. and then do something else – that was an entirely selfish statement that I regretted the instant I said it. Our shared dream, in my mind, was that we would be professors together. I was clinging to that, not considering her needs. As soon as a said it I realized that what I was dreaming of was no longer our shared dream and hadn't been for quite some time. In shame, I pivoted instantly, and told her that she should choose whatever would make her happy.

But saved in the notebook where she wrote the above entry, was the church bulletin for that same day. Clearly it spoke to her. On the front was a quote from Henri Nouwen that I suspect helped her with the guilt she felt:

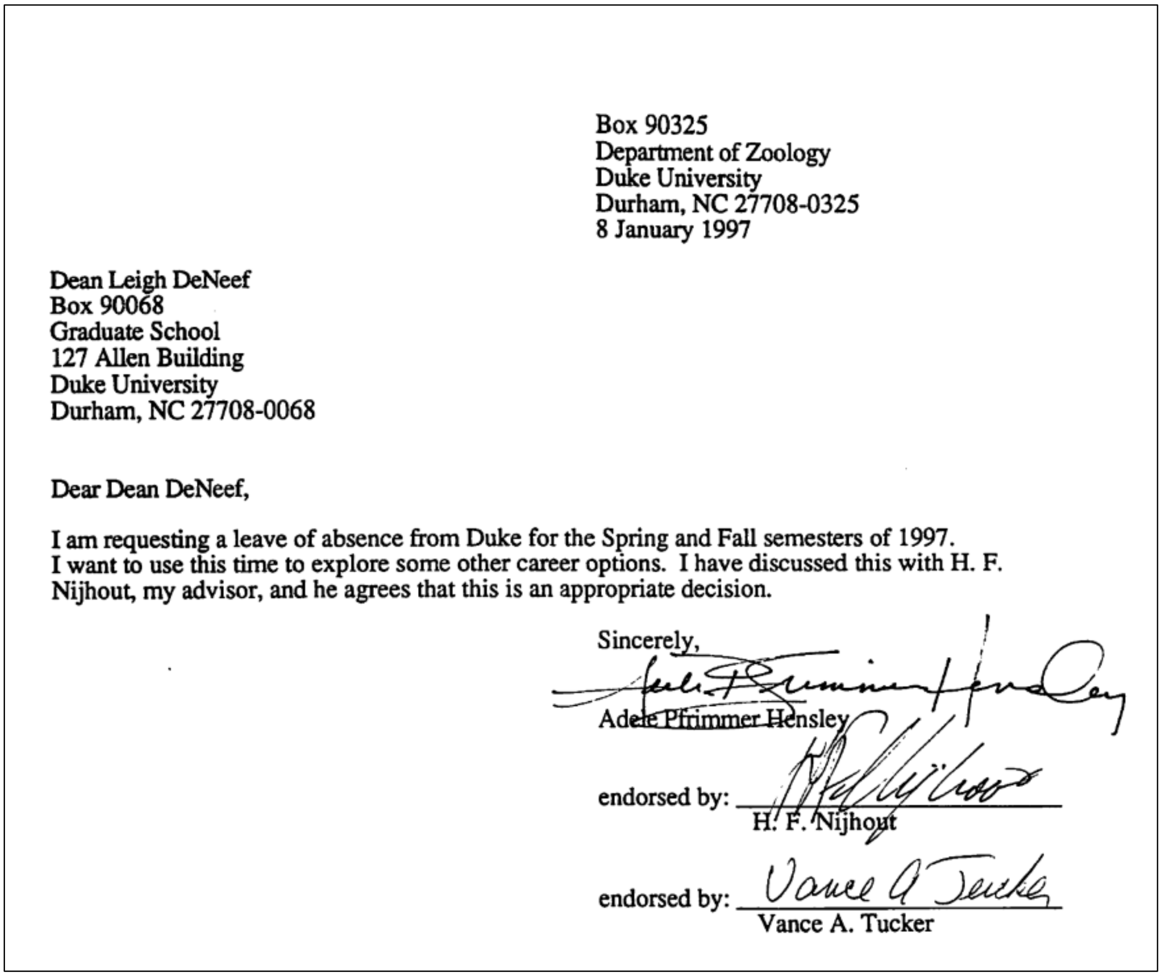
> *Self-rejection is the greatest enemy of the spiritual life because it contradicts the sacred voice that calls us the "Beloved." Being the Beloved constitutes the core truth of our existence.*

The Corporate Confession that Sunday included:

> *With you there is forgiveness, and we ask for it. Renew a right spirit within us and send us on our way, rejoicing. Amen.*

The anthem that day was "For the Beauty of the Earth" by John Rutter which is rich in gratitude for both nature and the love of family and friends. Adele always loved to sing it, but I think this particular week it was part of bringing her to peace with changing careers.

1997



Box 90325
Department of Zoology
Duke University
Durham, NC 27708-0325
8 January 1997

Dean Leigh DeNeef
Box 90068
Graduate School
127 Allen Building
Duke University
Durham, NC 27708-0068

Dear Dean DeNeef,

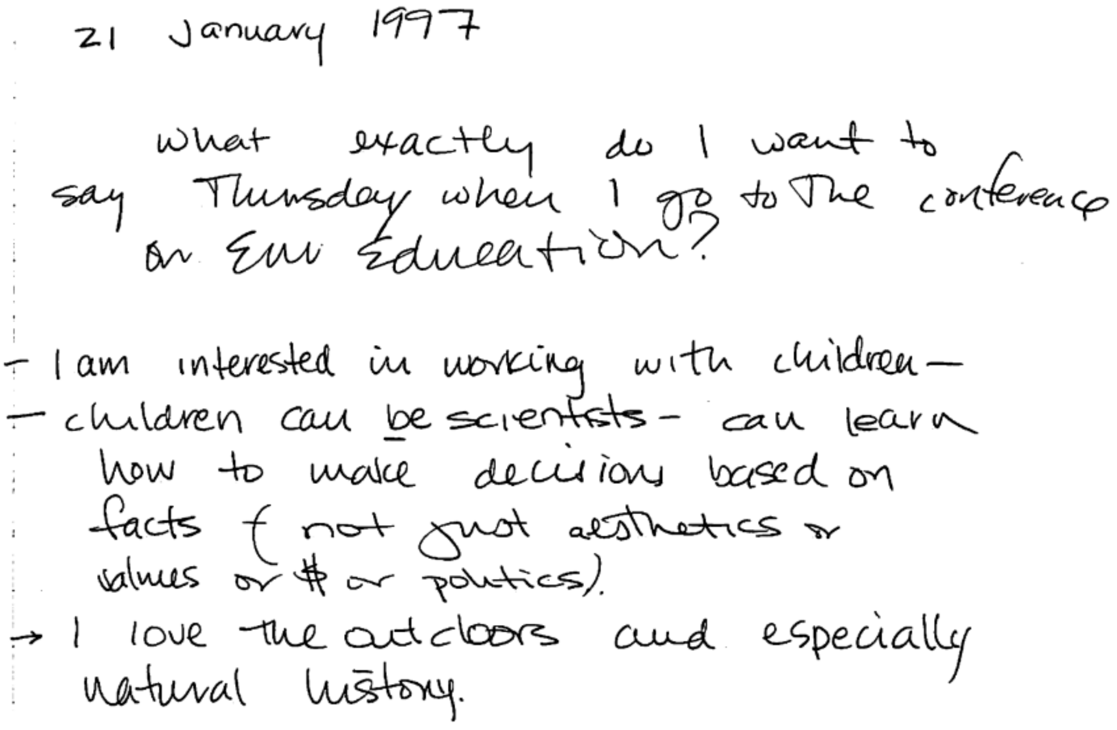
I am requesting a leave of absence from Duke for the Spring and Fall semesters of 1997. I want to use this time to explore some other career options. I have discussed this with H. F. Nijhout, my advisor, and he agrees that this is an appropriate decision.

Sincerely,

Adele Pfrimmer Hensley

endorsed by:
H. F. Nijhout

endorsed by: Vance A Tucker
Vance A. Tucker



21 January 1997

What exactly do I want to say Thursday when I go to The conference on Env Education?

- I am interested in working with children —
- children can be scientists — can learn how to make decisions based on facts (not just aesthetics or values or $ or politics).

→ I love the outdoors and especially natural history.

What exactly do I want to say Thursday when I go to the conference on Env. Education?

- *I am interested in working with children*
- *Children can be scientists – can learn how to make decisions based on facts (not just esthetics or values or $ or politics).*
- *I love the outdoors and especially natural history.*

III. Finding Adele

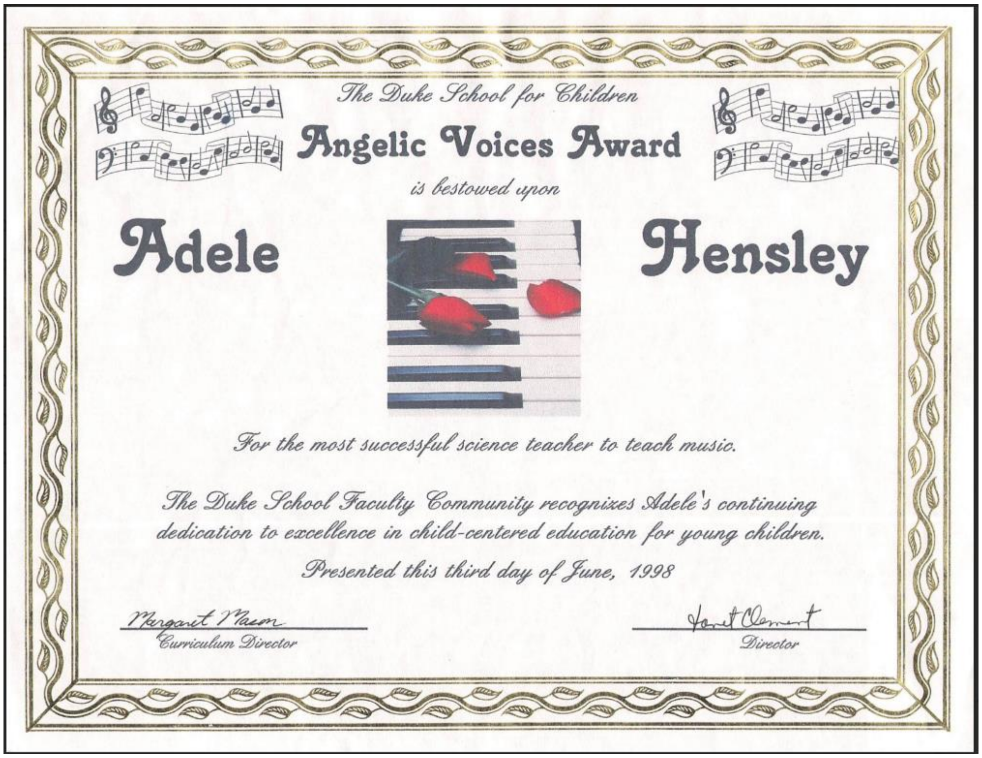
Leaving graduate school proved to be the right decision, albeit one she probably should have made earlier. But deciding to leave her Ph.D. program was fraught with concerns over letting people down, as much as taking care of herself. She wrote a lot in her journals about not disappointing her family, who had been so proud of her academic career for her entire life. She closed the door on a Ph.D., but she opened doors for other things that were fulfilling. Here’s how she summarized what came next, on her resume:

Natural Sciences Educator*, North Carolina State Museum of Natural Sciences, Raleigh, North Carolina, since April 1997. I develop and present interactive informal science programs for audiences consisting of children, teenagers and adults. These groups range in size from a handful to well over 150 people. I give two types of presentations. One is a time for visitors to meet a certain kind of animal. The other is a more question-driven natural history presentation. The topics I have presented have included gliding by plants and animals, adaptations for life in hot environments, winter dormancy, animal behavior, and flower structure and function. I also work with volunteers who take materials into the exhibit halls of the museum and give our visitors a hands-on experience.*

Music Teacher, Grades K-4*, Duke School for Children, 1516 Hull Avenue Durham, NC 27705. I teach music to children in kindergarten, and the first through fourth grades. My main objective this year has been to help the children listen to one another and sing together with a good unison sound. We have also spent much of our time exploring rhythm with our bodies, our instruments, and our voices.*

Duke School for Children

Adele didn't put that bumper sticker on her car; instead, she filed it away with her keepsakes. I guess it was too important to let it get ruined. Her jobs at DSFC and the Museum were transformative for her. And for me. I had a happy wife again! We agreed that neither of us should ever work a job we hated, just for a paycheck, if there was any alternative that brought us joy. And we stuck to that.



The Duke School for Children

Angelic Voices Award

is bestowed upon

Adele Hensley

For the most successful science teacher to teach music.

The Duke School Faculty Community recognizes Adele's continuing dedication to excellence in child-centered education for young children.

Presented this third day of June, 1998

Margaret Mason
Curriculum Director

Janet Clement
Director

Resigning from being a deacon at church had helped remove her sense of guilt and allowed her to reengage with people in a more productive and meaningful way. She had been avoiding church commitments and participation, feeling that whatever she did fell short of the expectations of a deacon. Officially separating from the obligations gave her the freedom to give what she could without worrying it wasn't enough. And so, she gave more and more. Each year the church members would all travel to the North Carolina coast for an All-Ages Beach Retreat. Adele was asked to help plan and lead it. Here's a bit of her brainstorming:

All Ages Beach Retreat--- ...I have called you friends... John 15:15 goals: Beloved Community, Deepen our Relationships, Enjoy one another/have fun Friday Evening 8:30 pm Orientation and Group Building Incorporations--about 12 categories Order, Order!--Oldest children/Middle Children/Youngest Children Go into Groups--who s your best friend? are you alike or different? how did you meet? ---FROM HERE, WE COULD MOVE BACK INTO THE BIG GROUP FOR A QUICK BRIEFING ABOUT THE PLAN FOR THE NEXT DAY AND THEN TWO OR THREE SONGS AND A PRAYER--Weave Us Together, Saturday Morning d like to see us do one or two games or songs that get people moving and playful together...then maybe we could talk about what it is that makes a friend, how to make friends (rather than just acquaintances), then we could break into groups to look at some friends in the Bible and maybe we could do some kind of interpretation of friends--maybe the Ecclesiastes, Exodus and Proverbs verses? OR Would you rather spend this time working on exercises about effective communicating? or something like that? two scriptures I'd like to emphasize Ecclesiastes 4:8-12 If one falls down, his friend can help him up but pity the man who has no one to help him up! Also, if two lie down together, they will keep warm. But how can one be warm alone? Though one may be overpowered, two can defend themselves. A cord of three strands is not easily broken.?

April 1997

Frank and I just had a big conversation—the When Will We Have Children conversation—and I have a sinking feeling the answer is never. I'm so sad about it. I feel like I'm grieving, but it's something that never happened. Frank says he has no desire to have a child right now, but that he thinks that if the job situation changed, he'd be ready. He's very careful about the whole issue of being able to afford it. I just want to fling caution to the wind and then we'd make it work out. Not a very satisfactory place plan for someone as I.T.[11] *as Frank is 😊. Why do I feel so heartbroken? Because I can't see that it'll ever be enough for him. I also feel in denial—like that he doesn't really mean it. But the thing is that he doesn't say things he doesn't really mean. I think he hasn't really said it because he didn't want to hurt me, but he really means it. One problem is it was always going to be hard to hear it. I feel like I'm cut off from my human destiny, but maybe I've been listening to too much Christian radio or reading or too much evolution and genetics. I watch Ron with Fia and Sandy with Debbie and I know absolutely that's what I want. I am reluctant to put that dream away. Is it a dream or is it a fantasy? I don't want to, but I can at least tuck it up into a safe closet for a while. But I will feel bad about it at least today, so it doesn't build up in me to a global sadness. Part of me says I'm stupid for crying but the rest of me knows that it's a real grief.... Am I stupid about my life? I don't know. I don't know why I'm so moronic (I'm not!), crying to think Frank wanted to have a family with me. I used to think it was because we were in school and when that was over, we'd get on with our family life. Well since I'm situated with my school now, what am I? What will I be? Help, Help, Help, Help, Help !!!!!!!!!!!*

[Illegible] *I used to sort of—not jokingly—tell Frank that he'd better* [illegible] *tell me soon if we were never having babies, because if we aren't I wasn't wasting my life on someone who wouldn't have children. I was having them with him or without him. Truth be told, I don't want that. I want Frank. I love him. I want to be with him forever. I don't want to leave him. The security of him. The home of him. The playfulness and friendship of him. Frank and I are a*

---

[11] My Myers-Briggs type seems to be ISTJ, if you buy into that personality categorization.

good match for each other. I don't want to [illegible] *that for some child I don't even know yet who wouldn't even be his. I love Frank. I wish we wanted the same thing. Rats.*

Adele's dear friend since high school, Rev. Sandy O'Quinn West, tells the tale of their spring 1997 adventure:

The Trip Where We Didn't Die

During our twenties, when we were old enough to know better, we set out to hike the Appalachian Trail. We planned to begin at the southern terminus, near Dahlonega, Georgia, which was just between our two homes in Birmingham, Alabama, and Aiken, South Carolina. Adele would make friends wherever she went, so when we settled down at a camping spot and saw a young man we had encountered earlier that afternoon, we of course invited him to our campfire to share a meal. Since he set up his backpacking tent a respectable distance away from ours, brought his own vegetarian rations and had a symphony parking pass on his windshield, I thought we were safe. Given that he seemed to be a gentle black soul from California, far from home, who probably didn't know what he had gotten himself into camping alone in the north Georgia mountains, Adele and I felt a bit protective of him and his safety. We had barely settled in for the night when the wind picked up, thunder rumbled, and lightning flashed. Adele and I ran for my minivan. But what about Jerome? We looked at each other in agreement, knowing we could not leave him alone in the storm. We invited Jerome to sleep in the back of the van with all our gear in the middle seat while we spent the night in the front seats. Was that a good choice? Would I advise my daughter to do the same? Absolutely not! Yet, we peacefully parted ways the next morning, our hearts a bit warmer from the passing friendship, wishing Jerome a safe journey as we headed to the AT.

Adele and Jerome

Our brief backpacking trip on the Appalachian Trail to Blood Mountain would not be so safe. Crossing paths with other backpackers is a characteristic of hiking the AT, and connecting with strangers was easy for Adele. It gave us pause when, as we were beginning our hike up Blood Mountain to the shelter, all the experienced hikers we met were heading down the mountain and into town because there was a hard freeze on the way. The multiple switchbacks and rocks to climb made us wonder why this trail was considered "moderate" but did not flag our confidence. We claimed victory when we made it to the gorgeous overlook at the top of Blood Mountain! We had hiked (the first few miles of) the AT! We celebrated with a cup of tea made over our backpacking stove.

It slowly began to dawn on us that maybe we were in trouble. We were sweaty and damp, it was getting cold, and the storm clouds were rolling in. Another couple of hikers looked at us like we were crazy as they hurried down to a warm room in town. There was no firewood to be found. No one else was around. Just as we were packing up to hike down before it got dark, lightning hit not far away, and the thunder made us jump. Before the steep hike down, we would have to cross several of the largest rock outcroppings I had ever seen. Should we stay and risk hypothermia, or hike down and risk getting hit by lightning? Adele and I donned our rain gear, waited for a lightning strike to pass, and ran with our gear over the outcroppings. The storm passed by the time we got to the waterfall and brook near the end of the trail, reminding us of Psalm 21, "He leadeth us beside still waters," and Psalm 42, "As the deer longs for streams of water, so my soul longs for you, O God." Our souls were at peace.

I wasn't sure Frank would ever let Adele go camping with me again.

Adele and Sandy (photo probably taken by Jerome).

May 1997

As she explored what to do with her future, Adele wrote a lot of journal entries. One day she explored her relationship with snakes. As a snake lover and snake biologist, I was thrilled to find this reflection among her writings. I had forgotten that she had told me about her childhood experience and forgotten being part of the later experiences with her. So, reading it in 2023 was fresh for me. We raised Clark to love animals, and of course, thanks to our influence, he loves snakes.

The first time I remember seeing a snake I was sure it was a venomous reptile, and it may well have been considering it belonged to my dad's Company or Battalion Commander. We lived in Georgia, and it was one of those summer evenings when it stays light outside until way past the bedtime of a six or seven-year old girl. Dad took me (just me!) with him, and we drove to Kmart and *walked back to my favorite part, the pet department. I looked at the fish while Daddy talked to the man and then the Kmart man got out a cardboard carton with tall sides and with handles. Dad picked out three or four mice. Wow, was I excited! Real mice, cute and furry. One was black and one was white with black blotches and one was brown; the other I don't remember. I'm sure I squealed with delight at the fuzzy little mice. The next thing I remember we were in my father's boss's office - it was a standard issue army office, wider than it was deep, with bright white walls. We were on the second floor at the end of the building and I could see the trees flowing in the breeze, shining green and golden in the summer sunlight. I said the office was a standard army office and it was except that in addition to the desk, table, chairs, file cabinets, and the book shelves it contained two aquaria. One was on the side of the room and it was on a stand so that its side was just even with my face. The other tank was higher at the end of the office next to the boss man's desk. I took in the details of the office in a minute because then my attention was riveted on the carton from Kmart. Dad was opening it and taking out the mice. "Why are you taking them out daddy? Are we going to play with them?" I don't know if I said that or just wondered it, but the next thing I knew the mice were in the aquaria and the snakes were constricting them. I remember the constricting, so they must not have been rattlesnakes. I imagine they were ratsnakes, but all my little girl eyes could see were that the little fluffy mice were going down the throats of those snakes. I don't remember anything else from that day after the shock of losing my incipient pets. I think I thought the snakes were neat but I pretty much dismissed the event after that. I don't know if I ever saw or touched another snake after that until I was in college and we worked with preserved materials, snakes that had been dead so long Strecker* [John K. Strecker, founding curator of Baylor's museum] *might have collected them himself. I thought Michael H's* [Baylor classmate, now a herpetologist] *menagerie was interesting but odd. Do we own more animals now than he did then? I don't remember.*

The first snakes I ever touched saw and handled on a daily basis were Rob G's [grad school classmate] *corn snakes in our office in Carr Hall at the University of Florida. Have I really been touching and knowing snakes more than 10 years? How is that possible? I think I just met so many snaky people once we moved to Gainesville that my inner revulsion was overcome by the deluge of ophidian* *splendor.* [In 1989 I purchased two hatchling kingsnakes that I named Goliath and Bathsheba. Adele and I spent hours reading in our shared office, each of us fidgeting with a live baby snake while we studied. Adele would let them twine into her hair where they would often settle, soaking up her warmth. Coincidently, at the adjacent desk, that's what I was soaking up, too.] *Even so, even with Goliath climbing through my Medusine hair when he was a first year kingsnake, I only ever went walking to look for snakes one time in Florida. Driving yes, a jillion times, but that is somehow safer more contained, and that time I went with Frank and HT3*[12] *and we were looking for cottonmouths, also known as water moccasins, Agkistrodon piscivorus, or "there's one kill it!"*[13] *This trip with HT3 was different for me because we were walking in the water looking for poisonous snakes that live in and near the water. We crept along feeling the bottom of the pond with our feet and I was sure that every log or stick I stepped on was going to turn into a cottonmouth and turn on me!*

Maybe I spooked them with my fear. Was it fear? It was the kind of adrenaline rush you get from a scary movie: lots of anticipatory dread but no real horror shock or sadness. Whatever it was, we didn't find any Agkistrodon that night. Right next to the pond, however, was the first pitcher plant I'd ever seen outside of a nature preserve on TV. Beautifully yellow and green and the pitchers were only about 10 centimeters tall and four centimeters across—nothing like the screen filling tricksters of television drawing their nourishment from fooling little flies. When I was a little girl during the years around the initial snake encounter, my father would read to us every night from Old Mother West Wind stories by Thornton Burgess. This was a series of just so stories told by Old Grandfather Frog to the Merry Little Breezes who were, of course, Mother West Wind's children. The payment the breezes had to make to hear a story was "fine fat foolish green flies." As a little girl I never imagined that a plant might demand such a sacrifice. Not in payment for a story, but to keep its little toehold in the Osceola National Forest.

The rest of that night, Frank, Harry, and I drove through the Osceola looking for snakes (was this the same trip or a later one with just me and Frank? [I don't

---

[12] Harry Tiebout was a more senior graduate student at the University Florida who shared an office with us, mentored us, and became a lifelong friend. He is variously referred to at Harry, Tiebout, HT, and HT3 in Adele's journals.

[13] Adele is lamenting this, not advocating killing snakes!

know either.]*) We drove those sandy roads but didn't see much, but just as the light was fading into that murky dusk that makes you wonder if you'll see again, a Pygmy Rattlesnake sitting in a beautiful coil, head up, was watching us and buzzing its rattle. Too dark for a photograph but was not too dark to leave its indelible mark on my mind! We drove some more and found that when the National Guard is on maneuvers all the good little snakes should stay in bed! We found the remains of several Canebrake Rattlesnakes, the southern coastal plain form of* Crotalus horridus*. Later just a bit, just about 10:00 PM when the roads had almost reached their late night coolest temperature, we saw a big movement* [illegible]*. We got out and I saw a gorgeous adult Canebrake exactly the same color as the* [illegible] *sandy road. With* [illegible] *and a red stripe offsetting white running the length of its back. I had the snake stick and had to keep the snake on the road until Frank could park the truck. Scared me! But it stayed and we got a fabulously long look at one of the few top predators a person in North America could ever contain on a road and spend that much time with. I never really pursued poisonous snakes after that night (Except for one day last summer; there are so many other snakes and other organisms I'd like to see.) but they pop into your life more often than you'd imagine.*

A couple of years ago I worked for a 4H camp for a month, leading students on explorations of the world of water. Wouldn't you know that equipped with scuba booties, a seine, and 20 children, the snake I'd see most commonly in a tributary of the Edisto River once every other day was Agkistrodon*. I got over my fear when I realized that these individuals always froze when they saw us; that as long as I could keep the kids from pawing under the bank, we'd be okay and so would the snakes. That's the amazing thing – Everyone you know will tell you about the "cottonmouth water moccasin" they found in their backyard pond, boat or dock, which they had to bludgeon (or hack, hoe, or shoot) into bloody bits. Nearly every snake a person does see near their water, boat dock, or backyard is some non-poisonous snake which, while it may have a* [illegible] *disposition and the right to protect itself, could no more hurt you than the neighbor's rose bush unless it spends much time swaying. I've walked past actual definitely defined WAMOS* [Water Moccasins] *and the most I've ever seen one do is lift its head up to look at me and maybe slink away.*

So all these years I've been knowing snakes and I've been seeing snakes but I always let someone else pick them up - get the glory - bag that sucker. One day I was out scouting for Chamaecrista [Partridge Pea, a host plant of caterpillars Adele studied] *a* Lampropeltis calligaster [the Mole Kingsnake, now called L. rhombomaculata] *crawled out on the trail in front of me. If it had been a dog we'd say rabbits stay away* [I have no idea what she means here.] *and I picked it put it in my pocket then in my hands It never* [illegible] *or bit. Special day! But it was a snake that picked me.*

Last Thursday Frank, Harry and I went back in the field together to snake lands, the sand hills of North Carolina. This time, for the first time in six or seven years, the place we stopped was a lonely bottomland full of meadows, hardwood forest, [illegible] *water ponds and a trail that went past all of them. Frank had found a racer, Harry naturally stumbled upon a WAMO, and I was just enjoying the day and watching them be manly snake hunters, mostly because there was no way I was going to try to pick up a snake. And have it anyway. I was just happy to see a snake after all. We hadn't seen but one racer on the way to the woods, and now on the way out the guys had caught three. To the left of the path was one of those hardwood forests that has been here long enough to have a layer of soft leaves but almost no undergrowth. Just tall trees, shade, and a soft place to walk. I walked in and saw a hollow tree. Earlier Frank and Harry had shared their hypothesis that Black Ratsnakes need hollow trees, so I thought well I'll see what I can see. The first snag was just a dead tree but from there I could see another one. It was also bare but showed lots of woodpecker holes and was near another snag. That one had lost most of its top and was only about 10 feet tall, an old pine tree. I walked around it softly and slowly. The tree was sort of orange and tan in the dark green forest light, and I was getting ready to move on. I looked down to my left and there against the base of the next tree was a 4 foot long Black Ratsnake,* Elaphe obsoleta, *big as life and twice as glossy, with her head on the root and her body kinked all the way from her neck back to her tail. I called the guys and they came. Frank and I speculated that she was kinked so because she'd eaten another snake, but HT3 pointed out that her tail was kinked too, so that couldn't be it. Harry took pictures. The snake sat still. Frank walked around the tree. The snake stood still. I said, "Can I pick her up?" and they told me it was my snake and I'd found it and it was my right. As a* [illegible] *herpetologist I* [was] *suppose*[d] *to pick it up. "Use your four fingers right behind her head," Harry told me. "Pin her down, then pick her up." It took me three tries. She went from being a stretched out squiggle to a coil after my first try, rattled her tail on the second try, and I actually picked her up on the third try. Then she shat on me and rattled some more but she never bit me and I was psyched! I felt capable, confident and cool even if it was just a Black Ratsnake, as Sandy said later. After I put her down, we watched her, and she slithered (Is there really any other word for it?) around the tree. This tree was hollow, too. She pulled into the base so that we could see her, but only through shadows. And then she deliberately but with all necessary speed climbed up the back of the hollow until she disappeared from view.*

About an hour later we drove past a controlled burn site, further south in the sand hills. They burned there to keep the pine tree habitat for the Red-cockaded Woodpecker and concern for the pine needle [illegible]*, and we saw a tree with a hollow shaped exactly like the Black Ratsnake's hollow, only this time instead of seeing a snake disappearing up the chimney we saw a fire completely filling the hollow, and this pine roaring like the warmest fire you'd have on the coldest night—a purifying fire cleansing the world of snakes, or for them?*

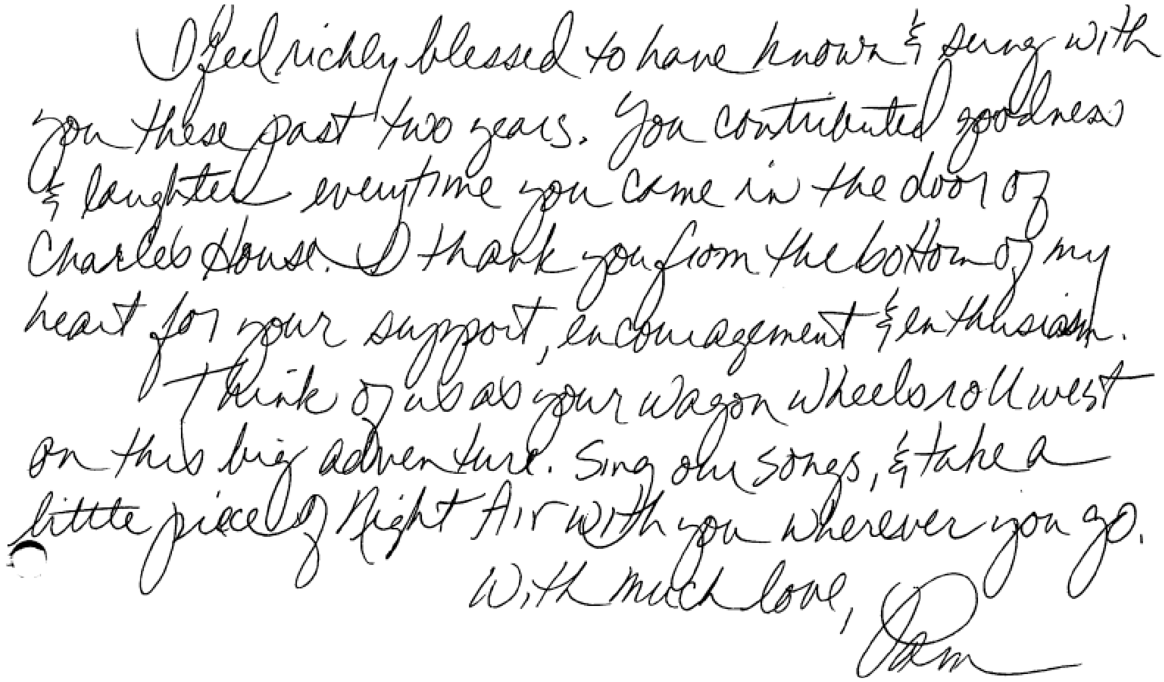
* * * * *

In the summer of 1997 Adele and I took our longest and most memorable road trip. We drove from Durham, North Carolina, to Whitefish, Montana, with our two Labradors, Blue and Rosie, in my little Ford Ranger pickup truck. Westbound, we stopped in Fort Worth to visit my sister Celest and her family, and then eastbound we took a more northerly route home to visit our friends Kurt and Marla in Kansas. We alternated between camping and staying with friends and family all the way there and back. We were on the road for about a month. It was therapeutic for Adele and such a good time for our marriage, giving us so many hours to talk about everything in our lives, our dreams for the future, her search for meaningful vocation and my search for a long-term job. We cherished the memories of this trip for decades after – not because there were any dramatic events but because it was just a time to be us and be together.

Spring 1998

I finally landed a tenure-track job, but for Adele that meant uprooting from her new careers in museum education and music education, leaving friends, and leaving all her singing groups. This was really difficult for her, on top of all the stress she had endured in graduate school. But Adele knew me well, so she knew all the reasons to do this with me. We didn't argue about this (we almost never argued about anything) because we knew where we were headed…buying a house and starting a family in the Arizona desert!

On our way, she got some of the sweetest goodbyes. Here's what Pam, leader of the Night Air group, wrote to her:



I feel richly blessed to have known & sung with you these past two years. You contributed goodness & laughter everytime you came in the door of Charles House. I thank you from the bottom of my heart for your support, encouragement & enthusiasm.

Think of us as your wagon wheels roll west on this big adventure. Sing our songs, & take a little piece of Night Air with you wherever you go.

With much love,

Pam

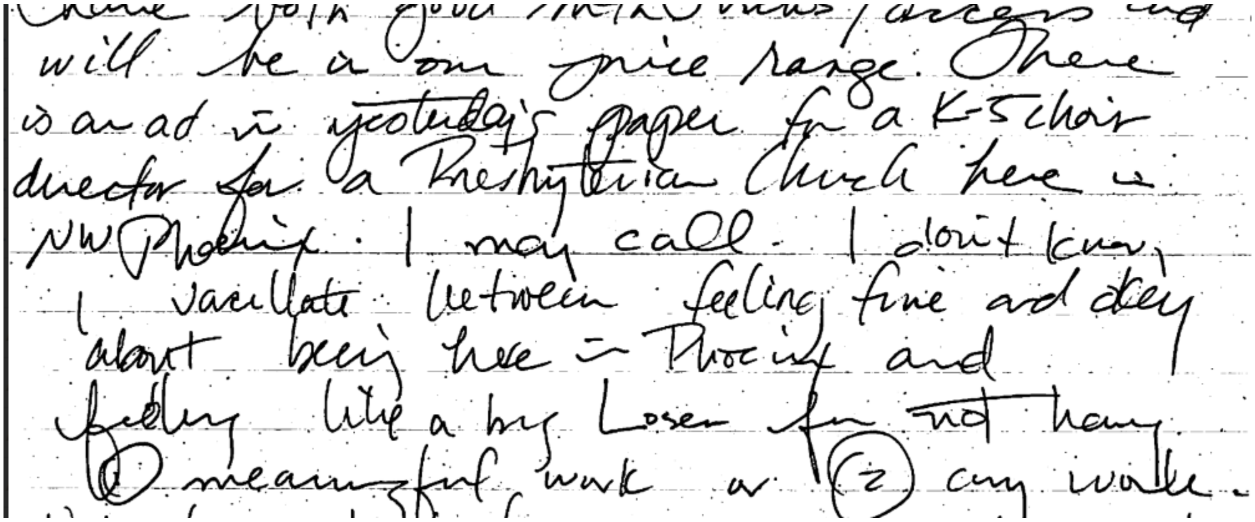
"I feel richly blessed to have known you & sung with you these past two years. You contributed goodness & laughter every time you came in the door of Charles House. I thank you from the bottom of my heart for your support, encouragement, and enthusiasm. Think of us as your wagon wheels roll out west on this big adventure. Sing our songs, & take a little piece of Night Air with you wherever you go.

With much love, Pam.

IV. Desert Rain

1998-2000

When I went to Arizona in April to interview for the job, I told Adele it felt like visiting another planet. Neither Adele nor I had ever been to the desert, but as nature lovers, we saw it as a great adventure. When we moved there, the college offered Adele some part-time teaching opportunities, but she was most excited to go the Desert Botanical Garden and take their training course for volunteers. She soaked up desert natural history from the Garden, and I spent a lot of time in the desert with my colleagues working on snake and turtle research. Soon Adele had all the expertise needed to lead tours of the DBG, and eventually to teach Arizona Flora at the college. She also became part of the education program at the Phoenix Zoo, driving the "zoo-mobile" to schools to show animals to students. I was insanely jealous when she learned to handle raptors, holding a Red-tailed Hawk or a Great-horned Owl on a big leather glove. The Arizona Game and Fish Department hired Adele into their education program, where she taught wildlife education workshops to schoolteachers and students.



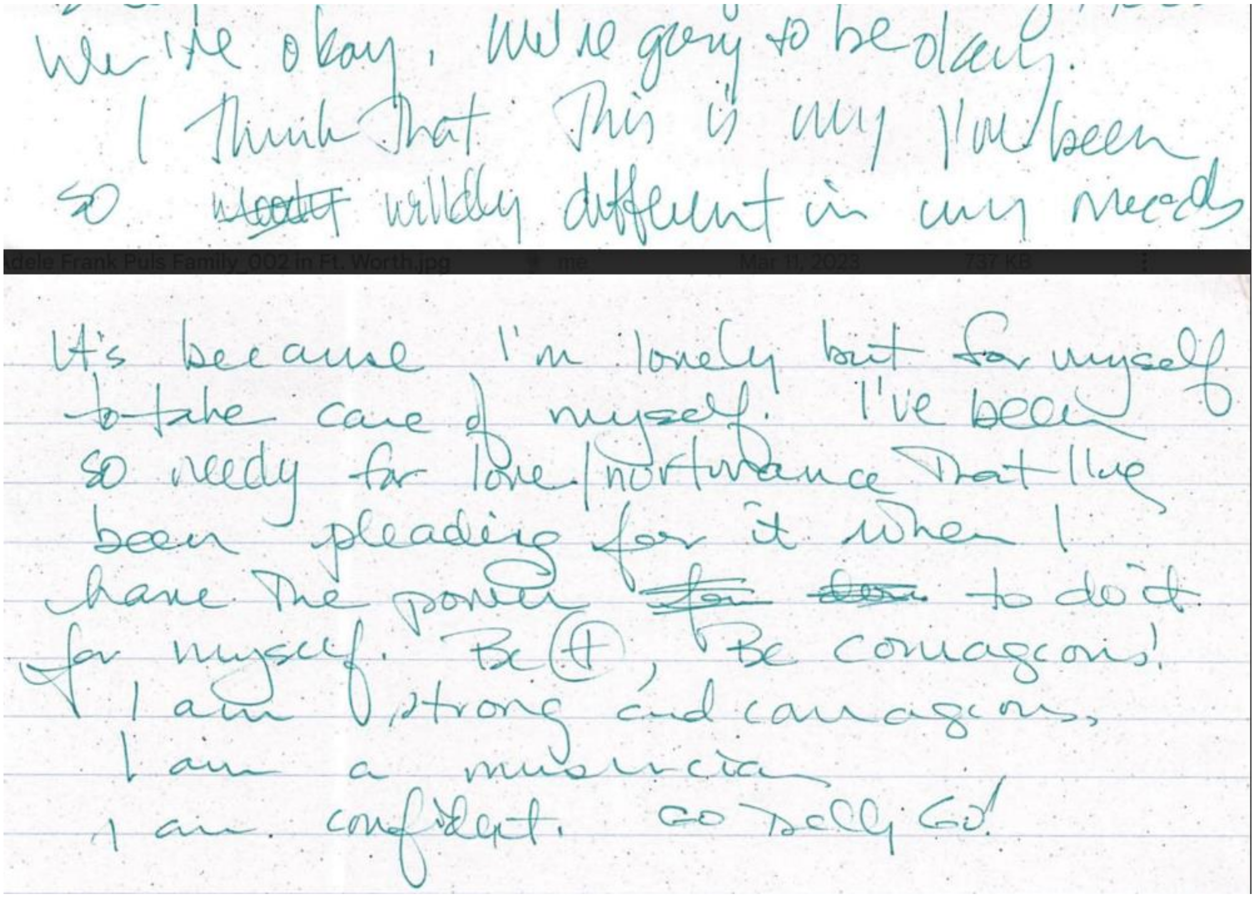
will be in our price range. There
is an ad in yesterday's paper for a K-5 choir
director for a Presbyterian Church here in
NW Phoenix. I may call. I don't know,
I vacillate between feeling fine and okay
about being here in Phoenix and
feeling like a big Loser for not having
① meaningful work or ② any work.

There was an ad in yesterday's paper for a K-5 choir director for a Presbyterian Church here in NW Phoenix. I may call. I don't know. I vacillate between feeling fine and okay about being here in Phoenix and feeling like a big loser for not having 1) meaningful work or 2) any work.

Shortly after we arrived in Phoenix, Adele was hired by Orangewood Presbyterian Church as a part-time Music Associate with Children. That November, just four months after we arrived, she wrote in her journal about leading a song, but she had no idea what it foreshadowed:

I started too low & rough in my throat and so did the children…

The transition to Arizona was difficult for Adele. If we had stayed in North Carolina, she would have been in line for a full-time job as an educator at the State Museum in Raleigh. But I had pulled her away from that prospect, from her singing group, from her church, and from dear friends. For me, Arizona was a big adventure from the outset, but for Adele it was all about recovering from losses, at first. Her counselor in North Carolina, Natalie, had helped her think about self-care in the same way a parent cares for and nurtures a child. This relationship between the two halves of her inner self was something she reflected on over and over in her journals. Ultimately, Adele was healed by sharing music with children and exploring the desert's rich biodiversity. The beauty of music, the beauty of nature, and her love for sharing these with other people all came together in Arizona.

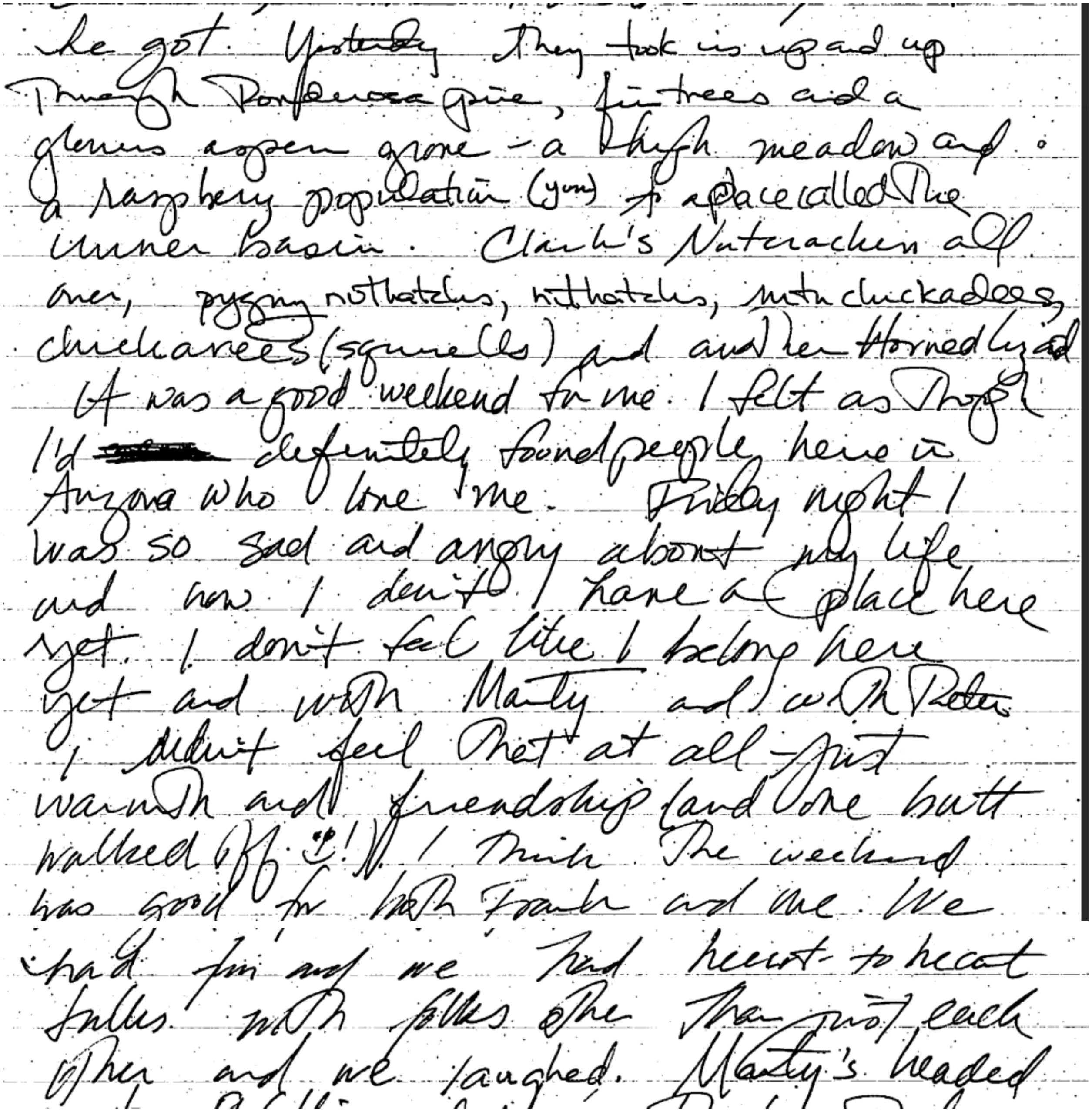


We're okay. We're going to be okay.
I think that this is why I've been
so ~~[illegible]~~ wildly different in my moods

It's because I'm lonely but for myself
to take care of myself. I've been
so needy for love/nurturance that I've
been pleading for it when I
have the power ~~for~~ ~~[illegible]~~ to do it
for myself. Be ⊕, Be courageous!
I am strong and courageous,
I am a musician
I am confident. Go Delly Go!

We're okay. We're going to be ok. I think that this is why I've been so wildly different in my moods. It's because I'm lonely but for myself to take care of myself. I've been so needy for love/nurturance that I've been pleading for it when I have the power to do it for myself. Be +, be courageous! I am strong and courageous; I am a musician. I am confident. Go Delly go!

Soon after we moved to Arizona, we were invited to visit my doctoral advisor Marty Crump and her family, who had migrated from Florida to Flagstaff a few years before. Here's part of what Adele wrote in her journal about that visit.

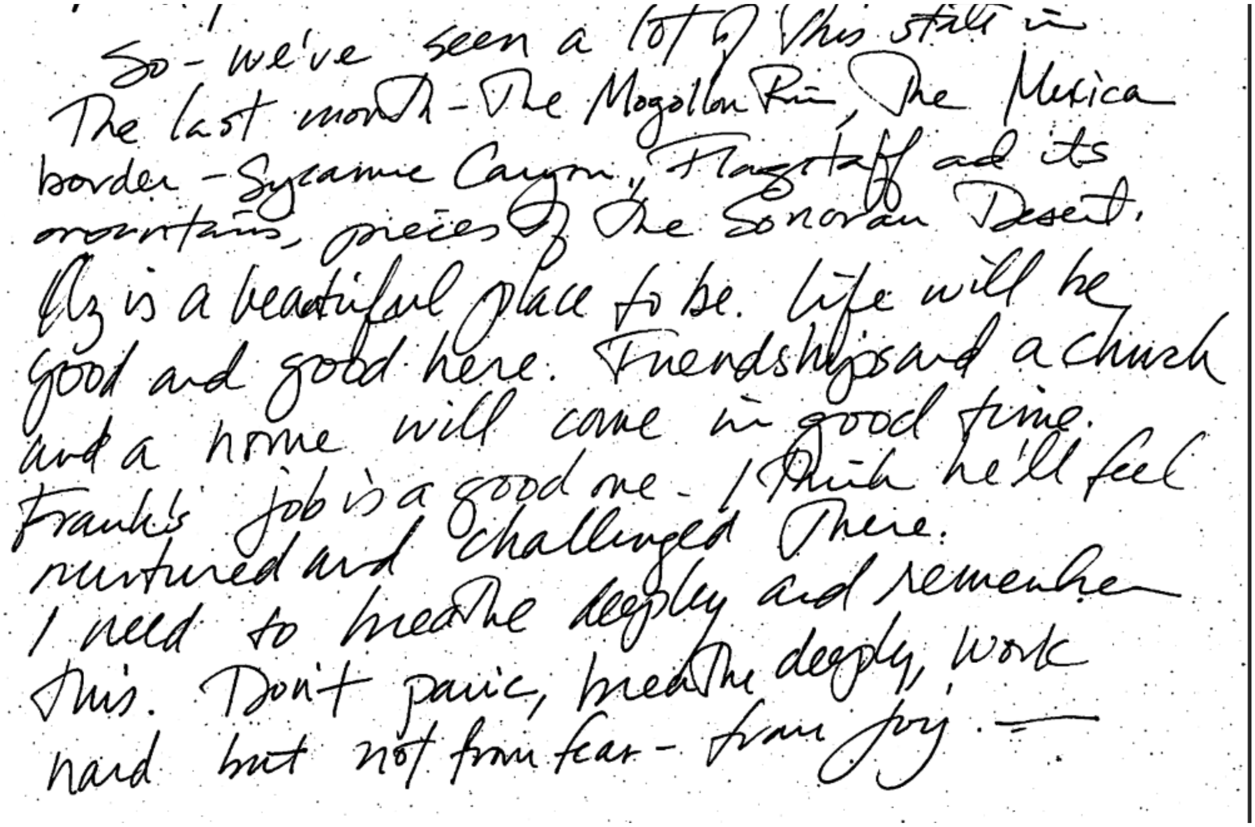


he got. Yesterday They took us up and up
Through Ponderosa pine, fir trees and a
glorious aspen grove – a high meadow and
a raspberry population (yum) to a place called The
Inner Basin. Clark's Nutcracker all
over, pygmy nuthatches, nuthatches, mtn chickadees,
chickarees (squirrels) and another Horned lizard
It was a good weekend for me. I felt as though
I'd [redacted] definitely found people here in
Arizona who love me. Friday night I
was so sad and angry about my life
and how I don't have a place here
yet. I don't feel like I belong here
yet and with Marty and with Peter
I didn't feel that at all – just
warmth and friendship (and one butt
walked off ☺!)! I think the weekend
was good for both Frank and me. We
had fun and we had heart-to-heart
talks with folks other than just each
other and we laughed. Marty's headed

8 September 1998

…

Yesterday they took us up and up through Ponderosa Pine, fir trees, and a gorgeous aspen grove – a high meadow and a raspberry population (yum) to a place called the Inner Basin. Clark's Nutcrackers all over, Pygmy Nuthatches, Nuthatches, Mountain Chickadees, chickarees (squirrels) and another horned lizard. It was a good weekend for me. I felt as though I'd definitely found people here in Arizona who love me. Friday night I was so sad and angry about my life *and how I didn't have a place here yet. I don't feel like I belong here yet and with Marty and with Peter I didn't feel that at all – just warmth and friendship (and one butt walked off) ☺! I think the weekend was good for both Frank and me. We had fun and we had heart-to-heart talks with folks other than just each other and we laughed.*

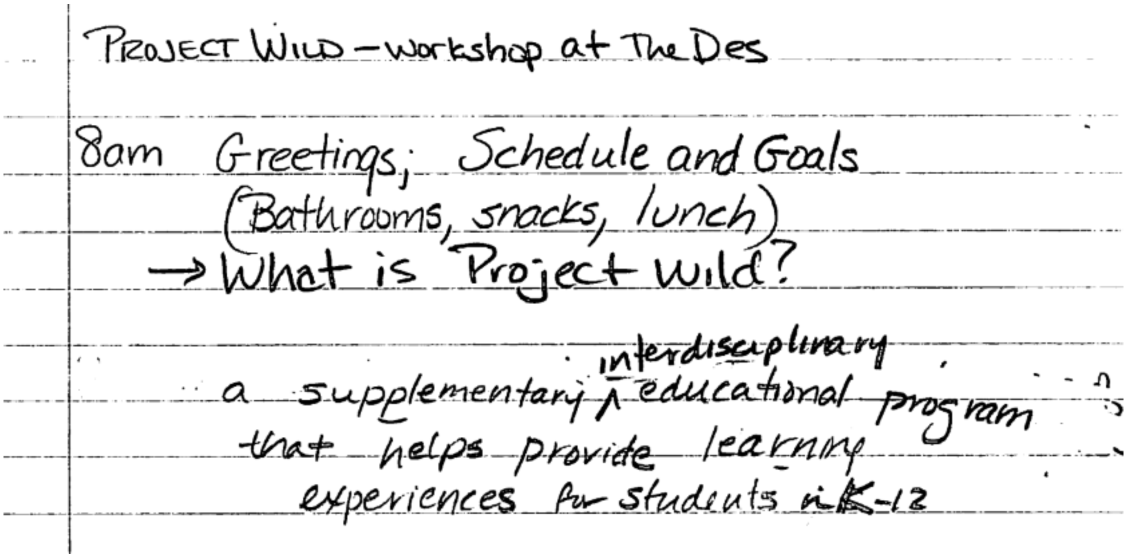


So - we've seen a lot of this state in
The last month - The Mogollon Rim, The Mexica
border - Sycamore Canyon, Flagstaff and its
mountains, pieces of the Sonoran Desert.
Az is a beautiful place to be. Life will be
good and good here. Friendships and a church
and a home will come in good time.
Frank's job is a good one - I think he'll feel
nurtured and challenged there.
I need to breathe deeply and remember
this. Don't panic, breathe deeply, work
hard but not from fear - from joy.

So – we've seen a lot of this state in the last month – the Mogollon Rim, the Mexican border – Sycamore Canyon, Flagstaff and its mountains, pieces of the Sonoran Desert. It is a beautiful place to be. Life will be good here. Friendships and a church and a home will come in good time. Frank's job is a good one – I think he'll feel nurtured and challenged there. I need to breathe deeply and remember this. Don't panic, breathe deeply, work hard but not from fear – from joy.

1999

Adele taught Project Wild workshops to teachers.

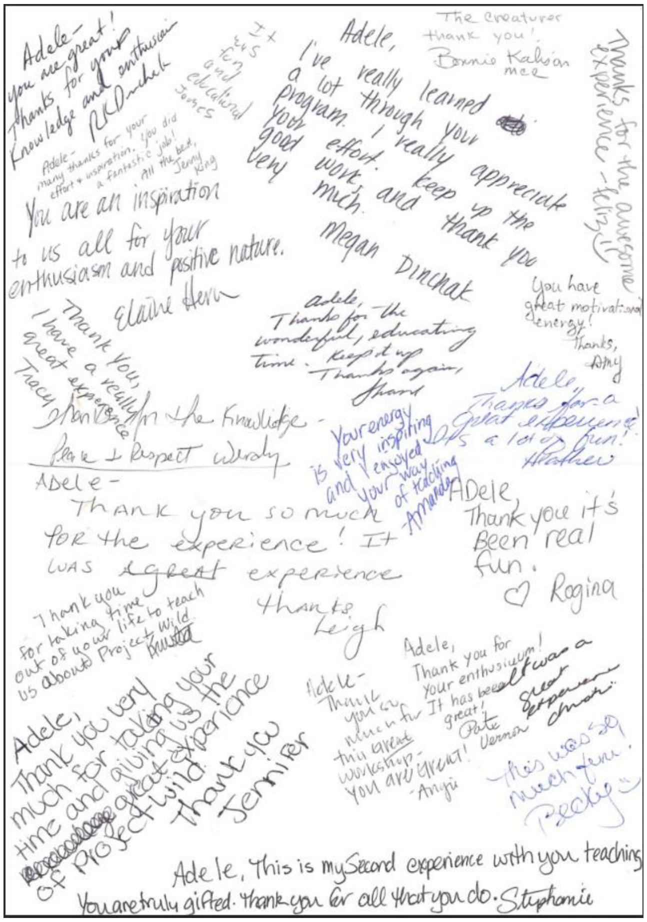


PROJECT WILD – workshop at The Des

8am Greetings; Schedule and Goals
(Bathrooms, snacks, lunch)
→ What is Project Wild?

a supplementary interdisciplinary educational program
that helps provide learning
experiences for students in K-12

And the teachers loved what she did.



Adele- you are great! Thanks for your knowledge and enthusiasm RK Dinchak

It's fun and educational Jones

Adele- many thanks for your effort + inspiration. You did a fantastic job! All the best, Jenny King

You are an inspiration to us all for your enthusiasm and positive nature. Elaine Hern

Adele, I've really learned a lot through your program. I really appreciate your good effort. Keep up the good work, and thank you very much. Megan Dinchak

The creatures thank you! Bonnie Kalsian

Thanks for the awesome experience - Feliz!

You have great motivational energy! Thanks, Amy

Adele, Thanks for the wonderful, educating time. Keep it up. Thanks again, Shari

Thank you, I have a really great experience Tracy

Thanks for the knowledge - Peace + Respect Wendy

Your energy is very inspiring and I enjoyed your way of teaching -Amanda

Adele, Thanks for a great experience! It's a lot of fun! Heather

ADele - Thank you so much for the experience! It was ~~a great~~ experience thanks Leigh

ADele, Thank you it's Been real fun. ♡ Regina

Thank you for taking time out of your life to teach us about Project Wild Krista

Adele, Thank you very much for taking your time and giving us the great experience of Project Wild. Thank you Jennifer

Adele- Thank you so much for this great workshop- You are great! -Angie

Adele, Thank you for your enthusiasm! It has been great! Pate Vernon

It was a great experience

This was so much fun! Becky :)

Adele, This is my Second experience with you teaching You are truly gifted. Thank you for all that you do. Stephanie

June 2000

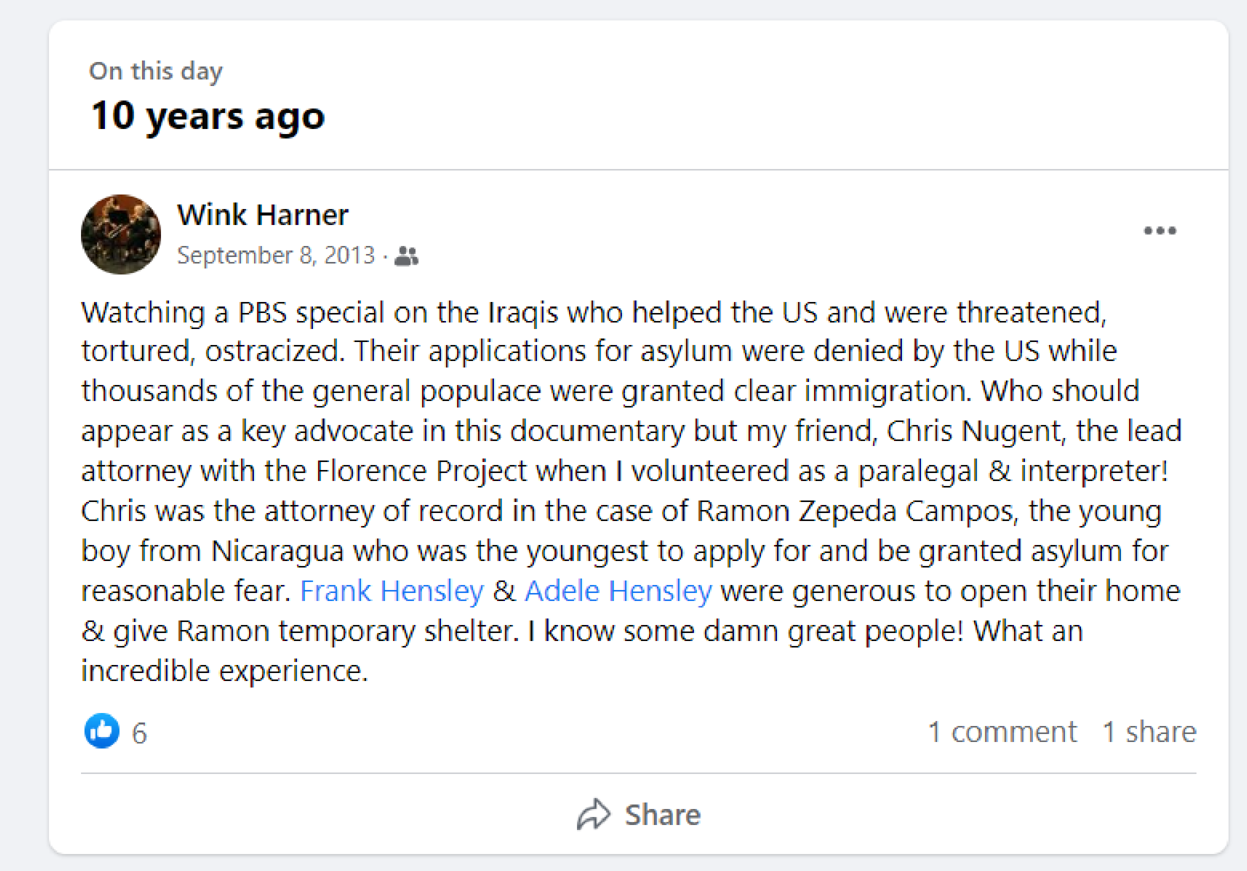
One Sunday at our church an announcement was made that a young refugee from Nicaragua was in urgent need of a temporary foster home, for just three or four days, preferably with a family that speaks some Spanish. As soon as she left the choir loft, Adele quickly made her way across the sanctuary toward me, but I knew before she spoke what was in her heart. I had trepidation about taking in a stranger with all the unknowns and risks. What if he stole from us? What if he tried to hurt us? Adele was pregnant and that raised my level of caution even higher. But Adele was fearless when it came to the decision. I hesitated, but her first impulse was love, not fear. … and thus, we invited Ramon to come stay with us.

Ramon was about 16 years old when he came to Arizona. After an early childhood of abuse and neglect that devolved into homelessness in his pre-teen years, he had become skilled at avoiding street gangs, working odd jobs for food, and even sleeping in a tree to evade both gang violence and police brutality. But Ramon eventually got caught and was severely beaten by police officers, who treated all homeless teens as gang members, regardless of their conduct. When he was released from the hospital, he vowed to find a better life, and headed north on foot. It took him a year to walk from Chinandega, Nicaragua to Tijuana, Mexico, where he found work and saved money until he could afford to pay a “coyote” to smuggle him across the border into the U.S. The coyotes would always advise juveniles to lie about their age if they got caught, so they would be quickly deported right back across the border. But that only works if the migrant is Mexican. Because he was Nicaraguan but claimed to be 18, Ramon was placed in detention with adult men from various other countries. Ramon was very small, perhaps 120 pounds, and very young, so in detention he became the target of further abuse. A non-profit group, The Florence Immigrant and Refugee Rights Project, provides *pro bono* legal and social services to detained refugees, and their lawyers were able to get the immigration court to recognize that Ramon was a minor, and release him to our custody.

Ramon spoke very little English and Adele spoke even less Spanish, but I managed to facilitate their communication. He later told me that at first, he was terrified by me, by the knives in our kitchen, and by not understanding what was happening to him. But Adele fed him, helped him wash his clothes, and sang so beautifully, that after a couple of days Ramon began to feel safe with us. Ramon began to enjoy riding Adele's bicycle, sweeping the kitchen floor every day "for Adela" and helping me with my Spanish. He thought it was very funny that I couldn't keep "*cuchara"* (spoon) and "*cuchillo*" (knife) straight.

Ramon's remarkable 5000 km journey, on foot and alone, actually drew the attention of major news organizations. The three of us were interviewed by María Elena Salinas on Univision, and a friend of ours saw it broadcast where she was living in Argentina. Ramon was featured in a Time Magazine story, too. I think about how Adele's fearless love overcame my hesitancy, and people around the world saw a glimpse of her compassion, even for just a moment.

Ramon lived with us almost a month, before being placed in a longer-term foster situation. Sadly, he ended up back in custody for a while, although this time in a somewhat safer juvenile detention program. Eventually, thanks to more *pro bono* legal representation and more people with compassion for children, Ramon was granted asylum in the United States, where he lives today. We've lost touch with Ramon, probably because of geography, the language barrier, and the fact that he was so young and his situation so volatile, that long-term connections didn't come easy to him. But even if we didn't make a life-long connection, I'm so proud of Adele's courage and grateful that she pushed me past my hesitation and that we reached out when we could.



10 years ago

Wink Harner

September 8, 2013 ·

Watching a PBS special on the Iraqis who helped the US and were threatened, tortured, ostracized. Their applications for asylum were denied by the US while thousands of the general populace were granted clear immigration. Who should appear as a key advocate in this documentary but my friend, Chris Nugent, the lead attorney with the Florence Project when I volunteered as a paralegal & interpreter! Chris was the attorney of record in the case of Ramon Zepeda Campos, the young boy from Nicaragua who was the youngest to apply for and be granted asylum for reasonable fear. Frank Hensley & Adele Hensley were generous to open their home & give Ramon temporary shelter. I know some damn great people! What an incredible experience.

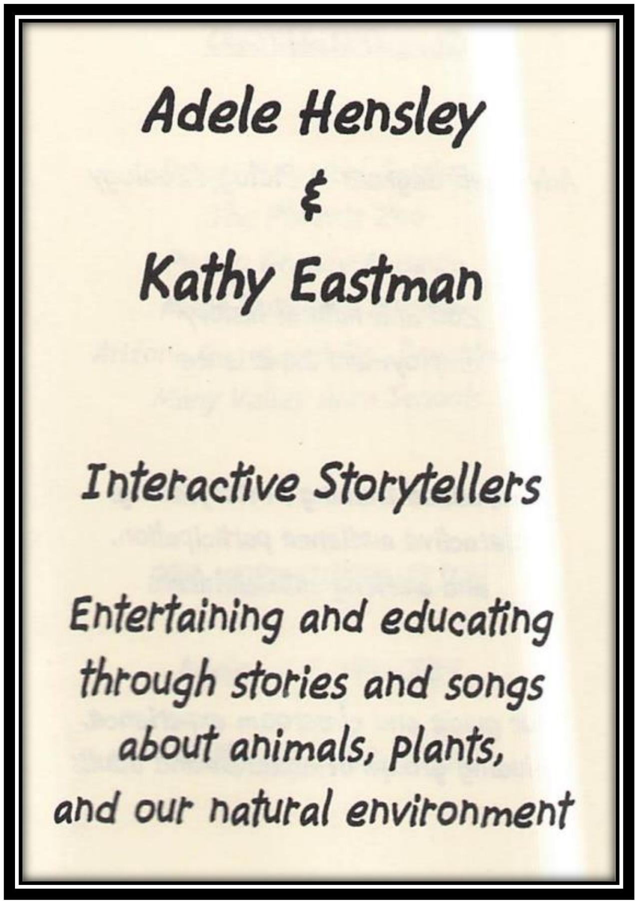
September 2000

Adele was pregnant through the blazing hot Arizona summer. But after the waiting comes the monsoon season with the blessing of rain. We waited 13 years to have a child. I was waiting for a Ph.D., a tenure-track job, and a house. Adele was waiting for me to be ready. Clark was worth the wait.

2001

Adele was so excited to be a mother, and to have a captive audience to teach about nature and to sing to. There was no escaping it…Clark was going to get detailed instruction in desert ecology from both parents! Lucky for him, the Spring of 2001 was a great year for wildflowers in the Sonoran Desert.

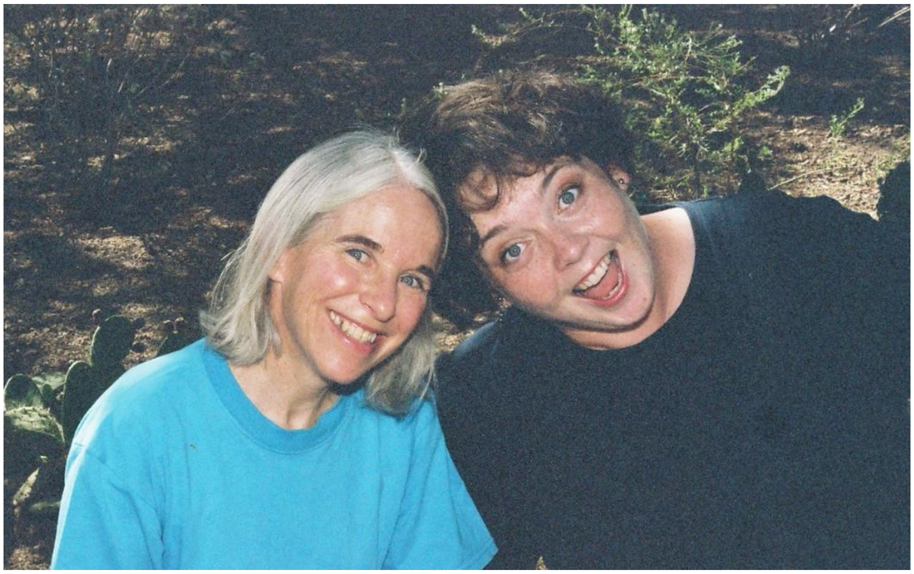
When we first arrived in Phoenix and Adele took the docent training class at the Desert Botanical Garden, Adele met Kathy and they became fast friends. Both had a strong interest in storytelling, and soon were partners in telling nature stories at various events and venues.

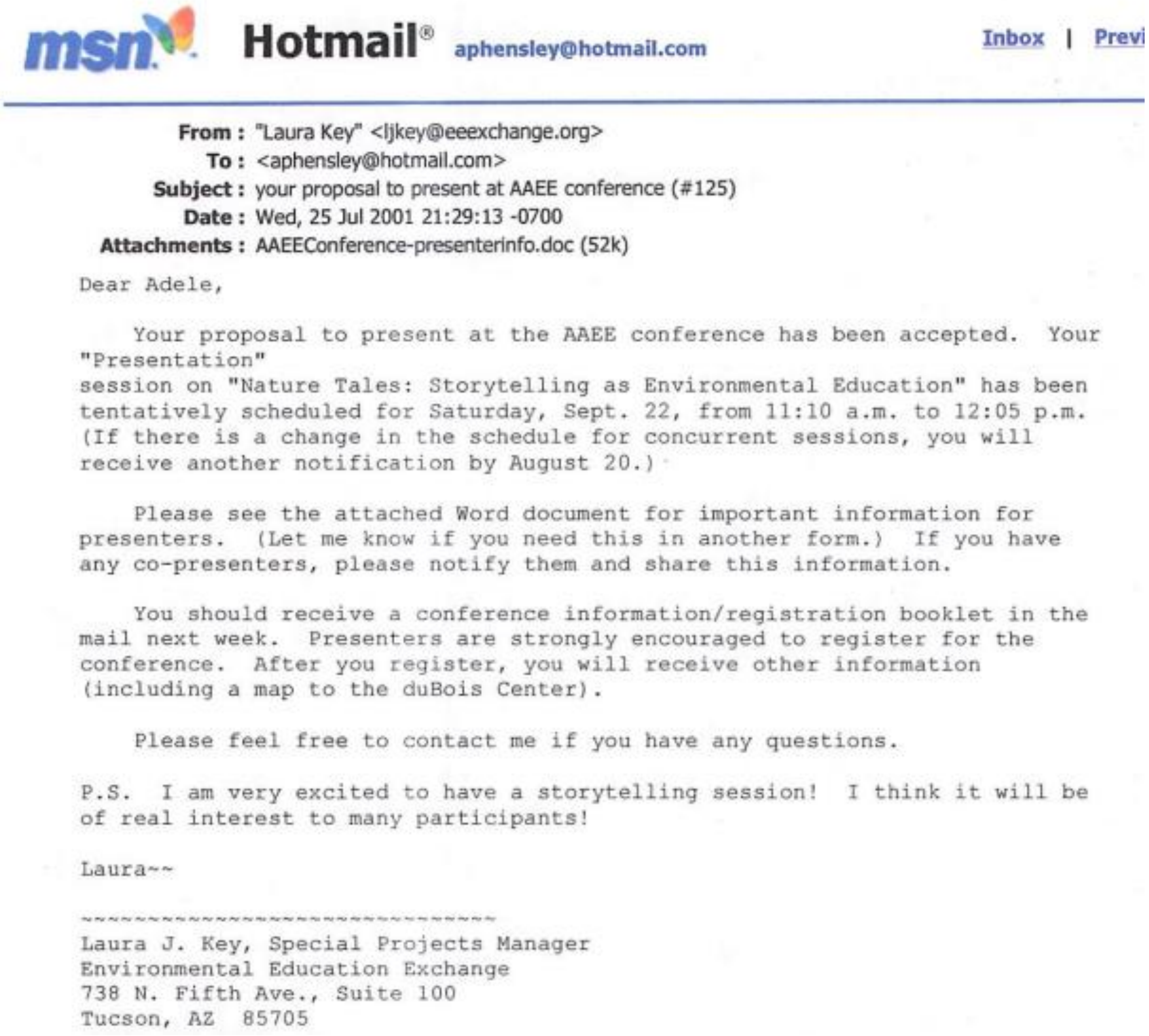


Adele Hensley
&
Kathy Eastman

Interactive Storytellers

Entertaining and educating
through stories and songs
about animals, plants,
and our natural environment





aphensley@hotmail.com

From : "Laura Key" <ljkey@eeexchange.org>
To : <aphensley@hotmail.com>
Subject : your proposal to present at AAEE conference (#125)
Date : Wed, 25 Jul 2001 21:29:13 -0700
Attachments : AAEEConference-presenterinfo.doc (52k)

Dear Adele,

Your proposal to present at the AAEE conference has been accepted. Your "Presentation" session on "Nature Tales: Storytelling as Environmental Education" has been tentatively scheduled for Saturday, Sept. 22, from 11:10 a.m. to 12:05 p.m. (If there is a change in the schedule for concurrent sessions, you will receive another notification by August 20.)

Please see the attached Word document for important information for presenters. (Let me know if you need this in another form.) If you have any co-presenters, please notify them and share this information.

You should receive a conference information/registration booklet in the mail next week. Presenters are strongly encouraged to register for the conference. After you register, you will receive other information (including a map to the duBois Center).

Please feel free to contact me if you have any questions.

P.S. I am very excited to have a storytelling session! I think it will be of real interest to many participants!

Laura~~

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

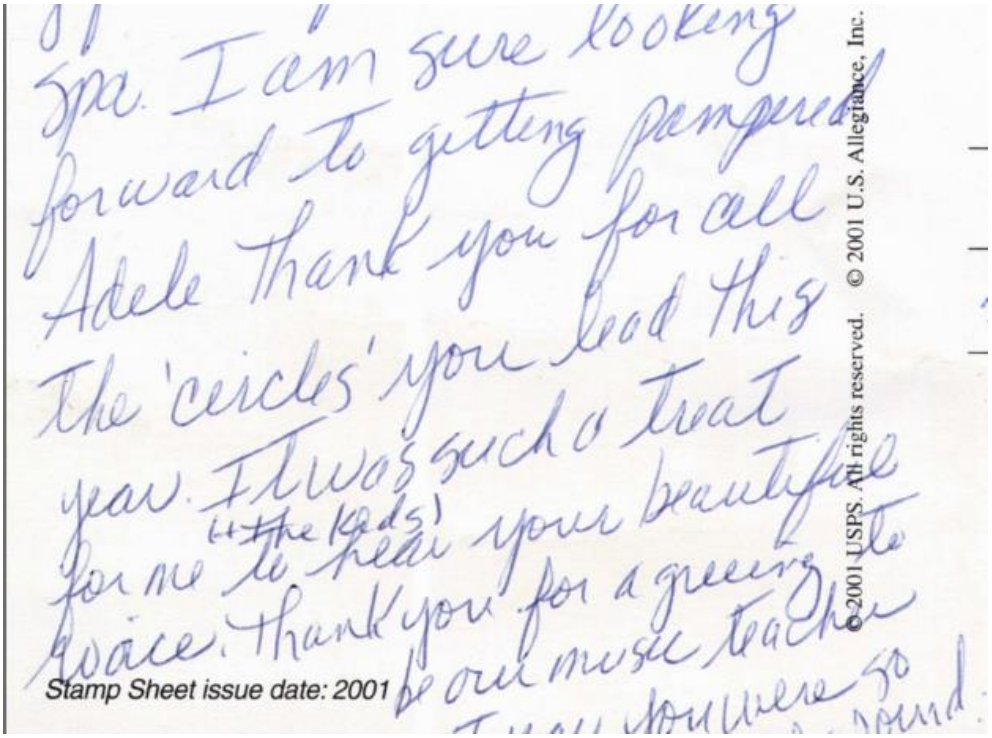
Laura J. Key, Special Projects Manager
Environmental Education Exchange
738 N. Fifth Ave., Suite 100
Tucson, AZ 85705
~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

August 2002

Adele noticed a persistent decline in her ability to sing the highest notes in her vocal register. After weeks of this, she made an appointment to see her primary care physician, Dr. Johnson. He saw her several times over a few months and referred her to a gastroenterologist and a speech therapist who tried to diagnose the problem. The gastroenterologist suspected her problem was acid reflux, and he proposed an experimental surgery, but her insurance declined to pay for it. The speech therapist brought in an otolaryngologist, who diagnosed her with spasmodic dysphonia, and began treating her with Botox injections into her vocal cords.

May 2003

Here's Adele doing what she loved best: singing with kids! (She's wearing a headset microphone and a speaker in a belt pack, to compensate for her weakening voice.)

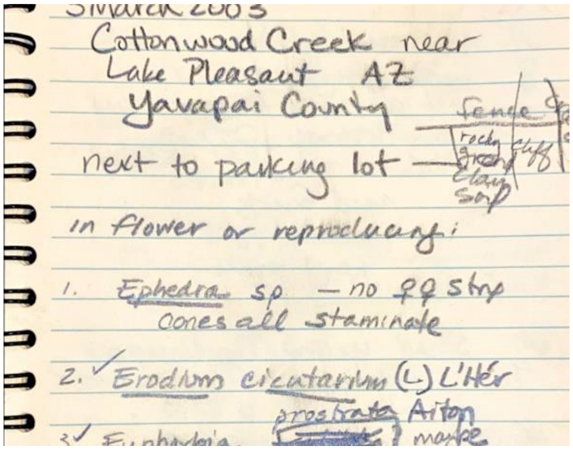


Spa. I am sure looking
forward to getting pampered.
Adele Thank you for all
The 'circles' you lead this
year. It was such a treat
for me (+ the kids) to hear your beautiful
voice. thank you for agreeing to
be our music teacher
you were so

Stamp Sheet issue date: 2001

At the end of the school year, Clark's teacher, Josie, wrote to Adele, "Adele thank you for all the 'circles' you lead this year. It was such a treat for me (+ the kids) to hear your beautiful voice. Thank you for agreeing to be our music teacher."

Adele taught Arizona Flora in 2003, and two of her students recently told me that they still use what they learned 20 years ago, either in their professional work in biology, or just in their enjoyment of nature.



3 March 2003
Cottonwood Creek near
Lake Pleasant AZ
Yavapai County

next to parking lot

fence
rocky cliff
gravel
clay
sand

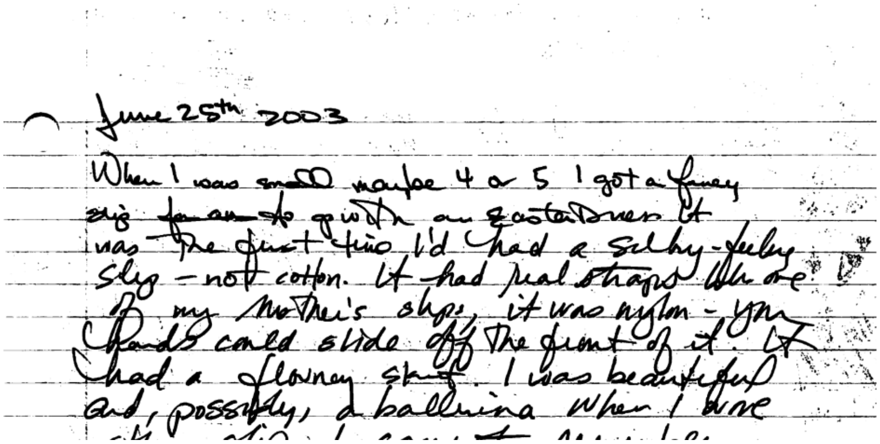
in flower or reproducing:

1. Ephedra sp — no ♀♀ strs
cones all staminate

2.✓ Erodium cicutarium (L) L'Hér

3.✓ Euphorbia prostrata Aiton
~~[illegible]~~ ? maybe

June 2003



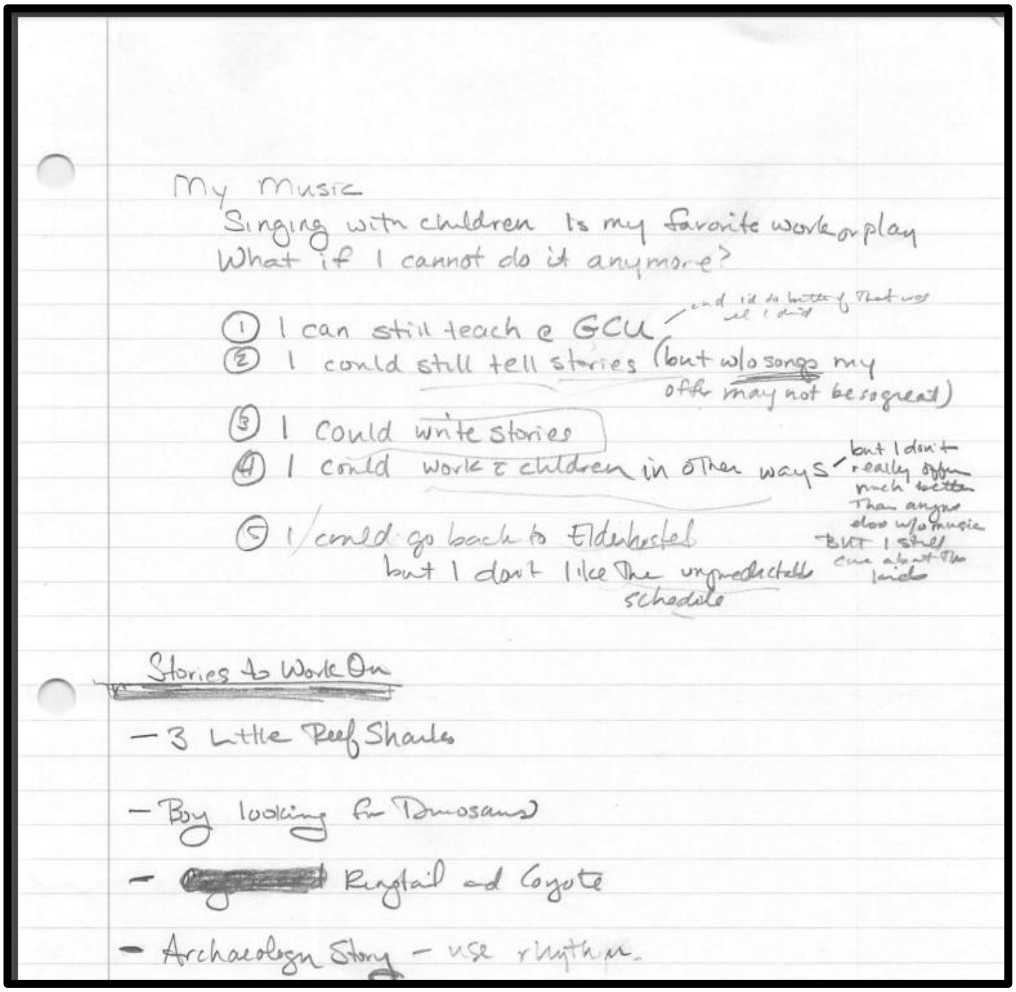
June 25th 2003

When I was small maybe 4 or 5 I got a fancy
slip ~~for an~~ to go with an Easter Dress. It
was the first time I'd had a silky-feeling
slip – not cotton. It had real straps like one
of my Mother's slips, it was nylon – your
hands could slide off the front of it. It
had a flowney skirt. I was beautiful
and, possibly, a ballerina when I wore

When I was small, maybe 4 or 5, I got a fancy slip to go with an Easter dress. It was the first time I'd had a silky-feeling slip – not cotton. It had real straps like one of my mother's slips. It was nylon- your hands could slide off the front of it. It had a [flowy? flowery?] *skirt. I was beautiful and, possibly, a ballerina when I wore the slip. I cannot remember ever wearing it under a dress. I have no idea what dress it went with. What I can remember is putting it on and going into my grandmother's very clean, very quiet, perfectly delicious living room, and dancing. I don't know what I danced to. I think I just danced to my own mind. I remember jumping up onto the piano bench and lying down. The slip would billow out like a parachute. I would pick out notes on the piano and dance some more. I could see myself in the mirror over the credenza in the foyer. Do people even call things foyers or credenzas anymore? I could see myself in the mirror over the dining room table. The lights from the fixtures reflected off the prisms in the chandelier above the dining table. I could roll on and off the sofa all because of the slip…the beautiful, simple, grown-up nylon slip.*

2004

My Music
Singing with children is my favorite work or play
What if I cannot do it anymore?



My Music
Singing with children is my favorite work or play
What if I cannot do it anymore?

① I can still teach @ GCU – and I'd do better if that was all I did
② I could still tell stories (but w/o songs my offer may not be so great)
③ I could write stories
④ I could work c̄ children in other ways – but I don't really offer much better than anyone else w/o music – BUT I still care about the kids
⑤ I could go back to Elderhostel
but I don't like the unpredictable schedule

Stories to Work On

– 3 Little Reef Sharks

– Boy looking for Dinosaurs

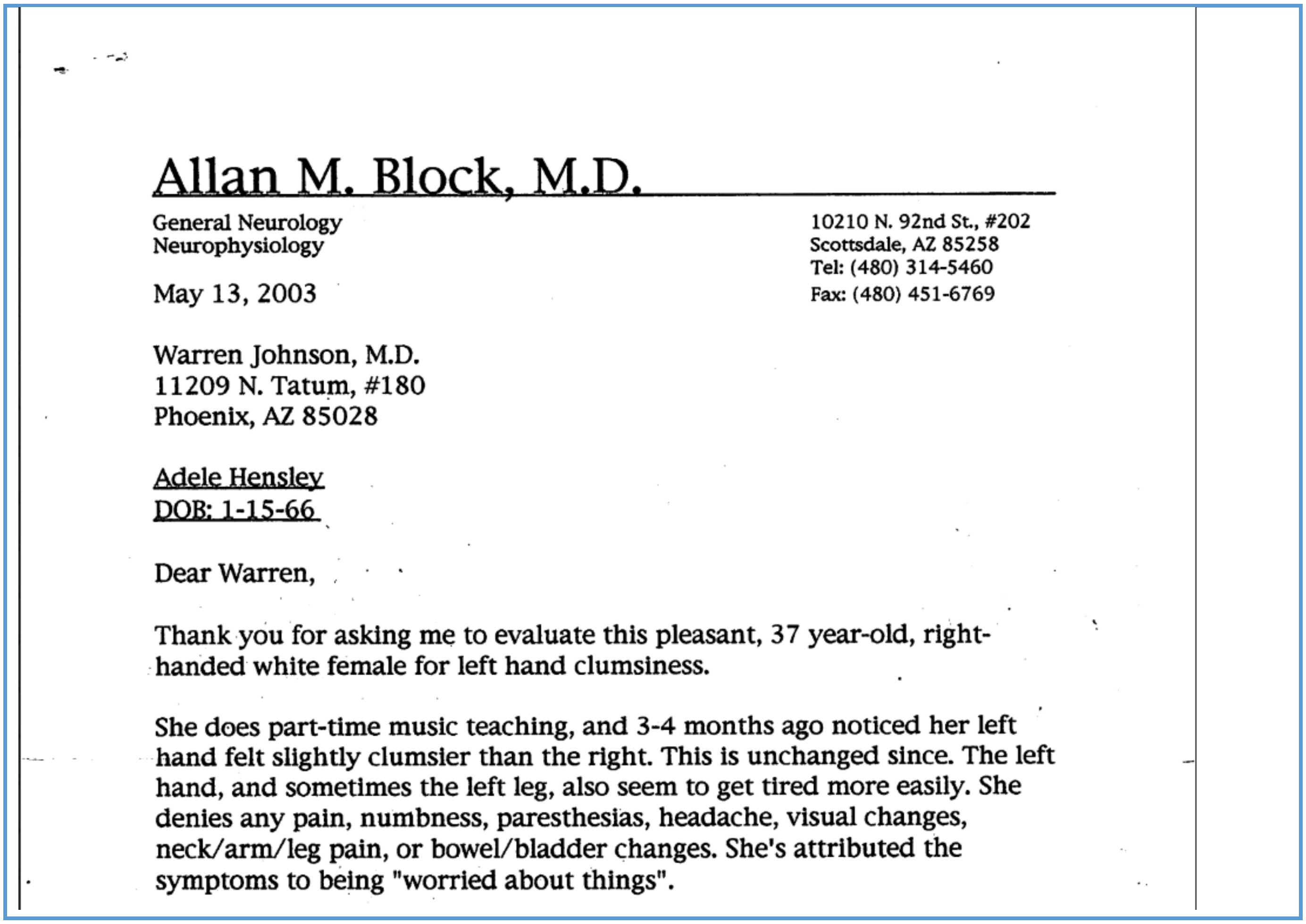
– [redacted] Ringtail and Coyote

– Archaeology Story – use rhythm.

V. Dx

2003-2005

A staple of children's music is singing *The Itsy-Bitsy Spider* and teaching kids the fun little hand motions that go with it. But in the spring of 2003, Adele found her left hand incapable of making the motions for the line "*Down came the rain…*" This was the symptom that she showed Dr. Johnson which led him to refer her to a neurologist.



Allan M. Block, M.D.

General Neurology
Neurophysiology

10210 N. 92nd St., #202
Scottsdale, AZ 85258
Tel: (480) 314-5460
Fax: (480) 451-6769

May 13, 2003

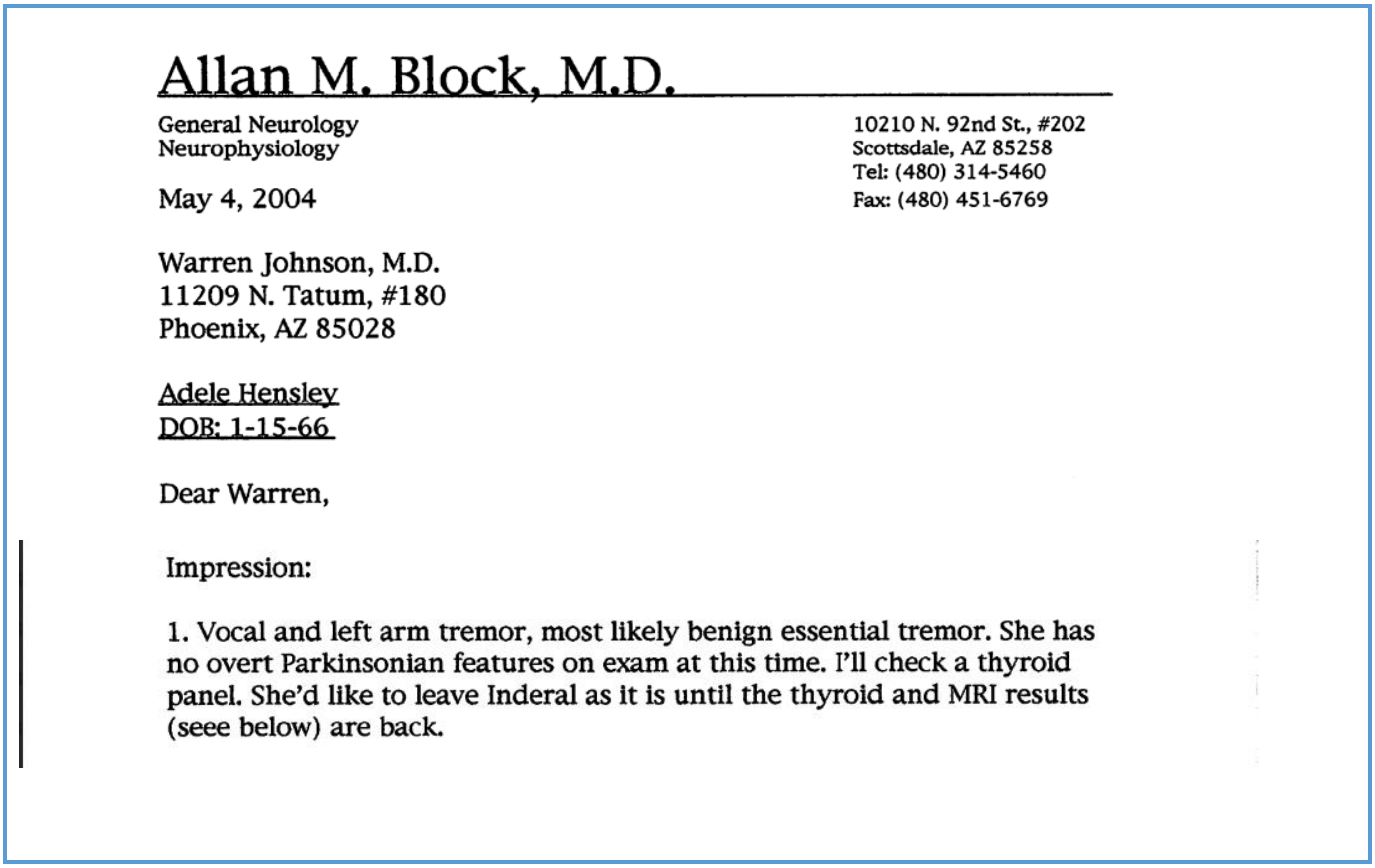
Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

Adele Hensley
DOB: 1-15-66

Dear Warren,

Thank you for asking me to evaluate this pleasant, 37 year-old, right-handed white female for left hand clumsiness.

She does part-time music teaching, and 3-4 months ago noticed her left hand felt slightly clumsier than the right. This is unchanged since. The left hand, and sometimes the left leg, also seem to get tired more easily. She denies any pain, numbness, paresthesias, headache, visual changes, neck/arm/leg pain, or bowel/bladder changes. She's attributed the symptoms to being "worried about things".



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May 4, 2004

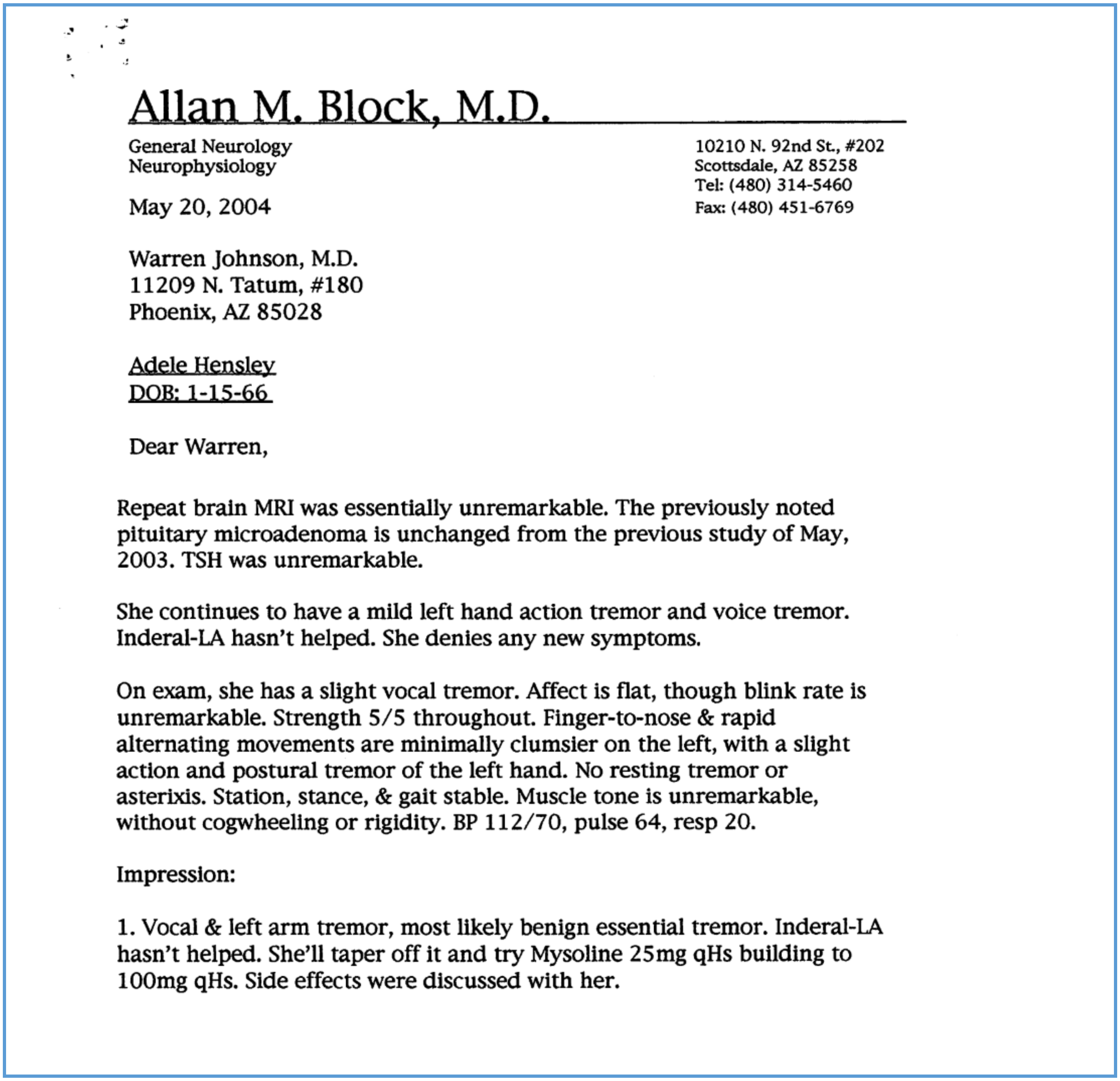
Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

Adele Hensley
DOB: 1-15-66

Dear Warren,

Impression:

1. Vocal and left arm tremor, most likely benign essential tremor. She has no overt Parkinsonian features on exam at this time. I'll check a thyroid panel. She'd like to leave Inderal as it is until the thyroid and MRI results (seee below) are back.



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General Neurology
Neurophysiology

10210 N. 92nd St., #202
Scottsdale, AZ 85258
Tel: (480) 314-5460
Fax: (480) 451-6769

May 20, 2004

Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

Adele Hensley
DOB: 1-15-66

Dear Warren,

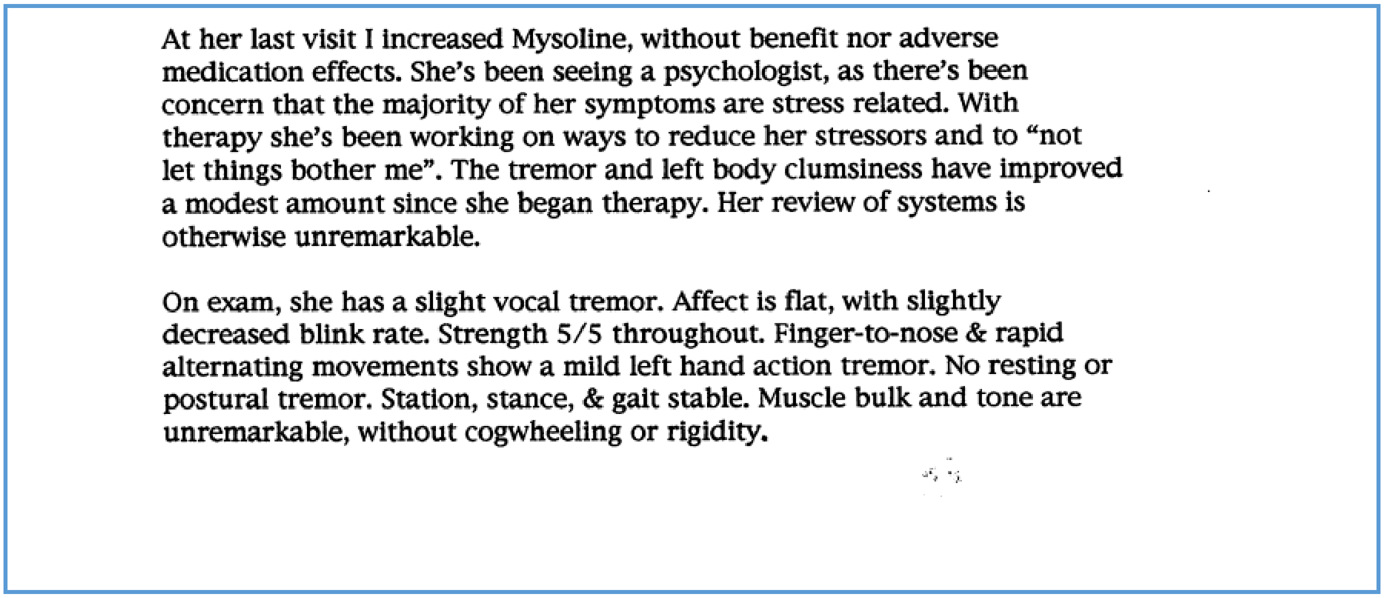
Repeat brain MRI was essentially unremarkable. The previously noted pituitary microadenoma is unchanged from the previous study of May, 2003. TSH was unremarkable.

She continues to have a mild left hand action tremor and voice tremor. Inderal-LA hasn't helped. She denies any new symptoms.

On exam, she has a slight vocal tremor. Affect is flat, though blink rate is unremarkable. Strength 5/5 throughout. Finger-to-nose & rapid alternating movements are minimally clumsier on the left, with a slight action and postural tremor of the left hand. No resting tremor or asterixis. Station, stance, & gait stable. Muscle tone is unremarkable, without cogwheeling or rigidity. BP 112/70, pulse 64, resp 20.

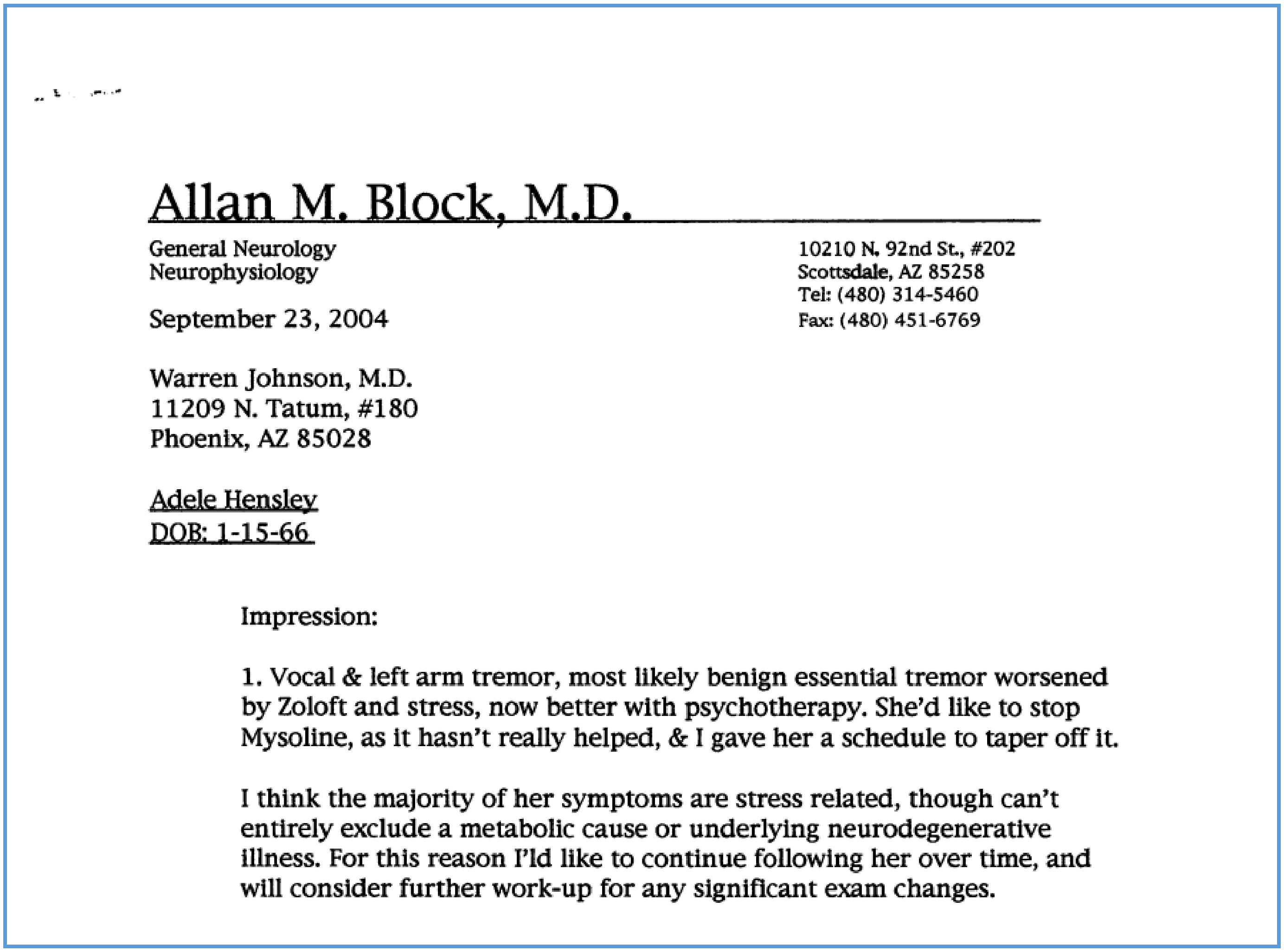
Impression:

1. Vocal & left arm tremor, most likely benign essential tremor. Inderal-LA hasn't helped. She'll taper off it and try Mysoline 25mg qHs building to 100mg qHs. Side effects were discussed with her.



At her last visit I increased Mysoline, without benefit nor adverse medication effects. She's been seeing a psychologist, as there's been concern that the majority of her symptoms are stress related. With therapy she's been working on ways to reduce her stressors and to "not let things bother me". The tremor and left body clumsiness have improved a modest amount since she began therapy. Her review of systems is otherwise unremarkable.

On exam, she has a slight vocal tremor. Affect is flat, with slightly decreased blink rate. Strength 5/5 throughout. Finger-to-nose & rapid alternating movements show a mild left hand action tremor. No resting or postural tremor. Station, stance, & gait stable. Muscle bulk and tone are unremarkable, without cogwheeling or rigidity.



Allan M. Block, M.D.

General Neurology
Neurophysiology

10210 N. 92nd St., #202
Scottsdale, AZ 85258
Tel: (480) 314-5460
Fax: (480) 451-6769

September 23, 2004

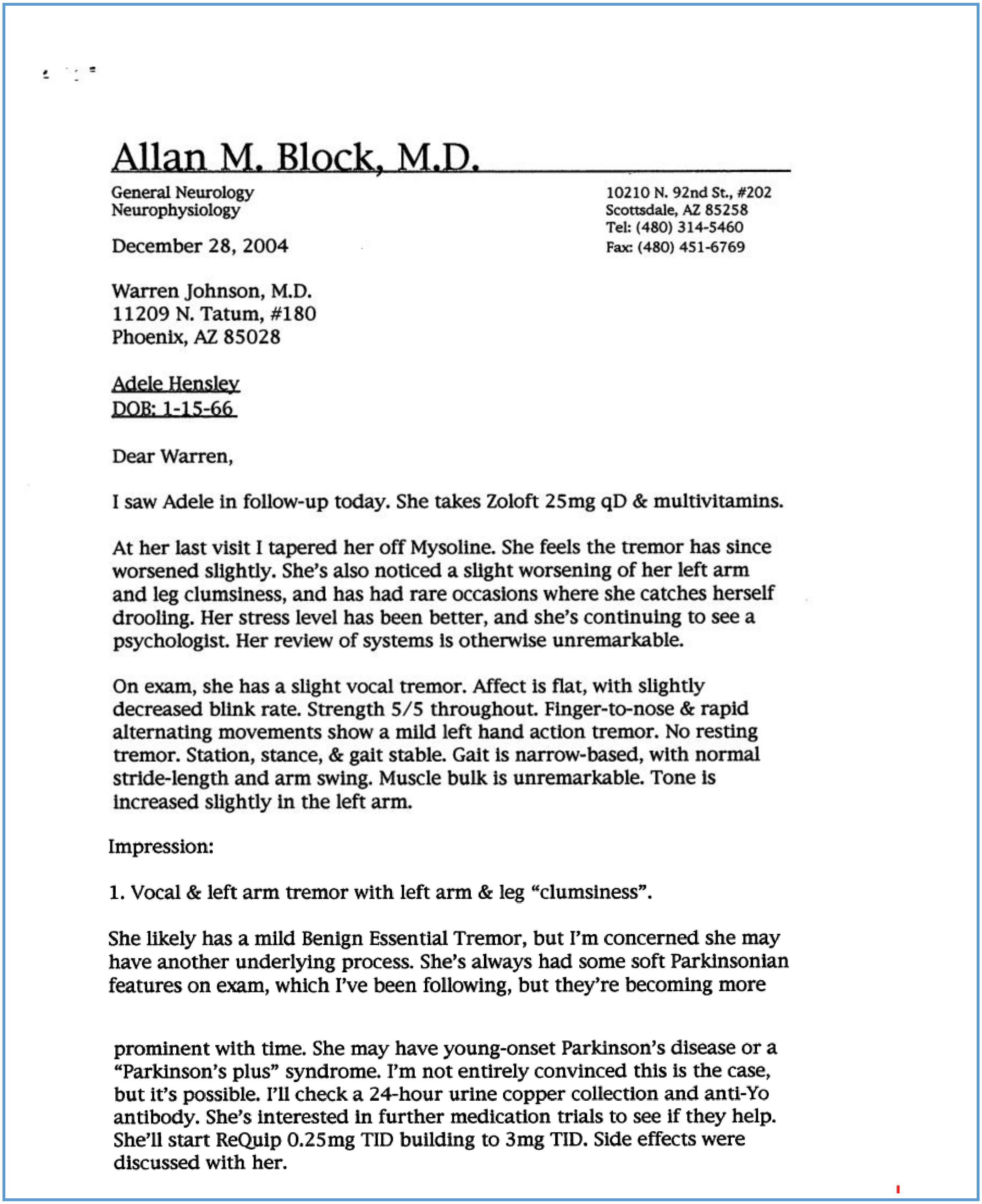
Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

Adele Hensley
DOB: 1-15-66

Impression:

1. Vocal & left arm tremor, most likely benign essential tremor worsened by Zoloft and stress, now better with psychotherapy. She'd like to stop Mysoline, as it hasn't really helped, & I gave her a schedule to taper off it.

I think the majority of her symptoms are stress related, though can't entirely exclude a metabolic cause or underlying neurodegenerative illness. For this reason I'ld like to continue following her over time, and will consider further work-up for any significant exam changes.



Allan M. Block, M.D.

General Neurology
Neurophysiology

10210 N. 92nd St., #202
Scottsdale, AZ 85258
Tel: (480) 314-5460
Fax: (480) 451-6769

December 28, 2004

Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

Adele Hensley
DOB: 1-15-66

Dear Warren,

I saw Adele in follow-up today. She takes Zoloft 25mg qD & multivitamins.

At her last visit I tapered her off Mysoline. She feels the tremor has since worsened slightly. She's also noticed a slight worsening of her left arm and leg clumsiness, and has had rare occasions where she catches herself drooling. Her stress level has been better, and she's continuing to see a psychologist. Her review of systems is otherwise unremarkable.

On exam, she has a slight vocal tremor. Affect is flat, with slightly decreased blink rate. Strength 5/5 throughout. Finger-to-nose & rapid alternating movements show a mild left hand action tremor. No resting tremor. Station, stance, & gait stable. Gait is narrow-based, with normal stride-length and arm swing. Muscle bulk is unremarkable. Tone is increased slightly in the left arm.

Impression:

1. Vocal & left arm tremor with left arm & leg "clumsiness".

She likely has a mild Benign Essential Tremor, but I'm concerned she may have another underlying process. She's always had some soft Parkinsonian features on exam, which I've been following, but they're becoming more prominent with time. She may have young-onset Parkinson's disease or a "Parkinson's plus" syndrome. I'm not entirely convinced this is the case, but it's possible. I'll check a 24-hour urine copper collection and anti-Yo antibody. She's interested in further medication trials to see if they help. She'll start ReQuip 0.25mg TID building to 3mg TID. Side effects were discussed with her.

Anniversary

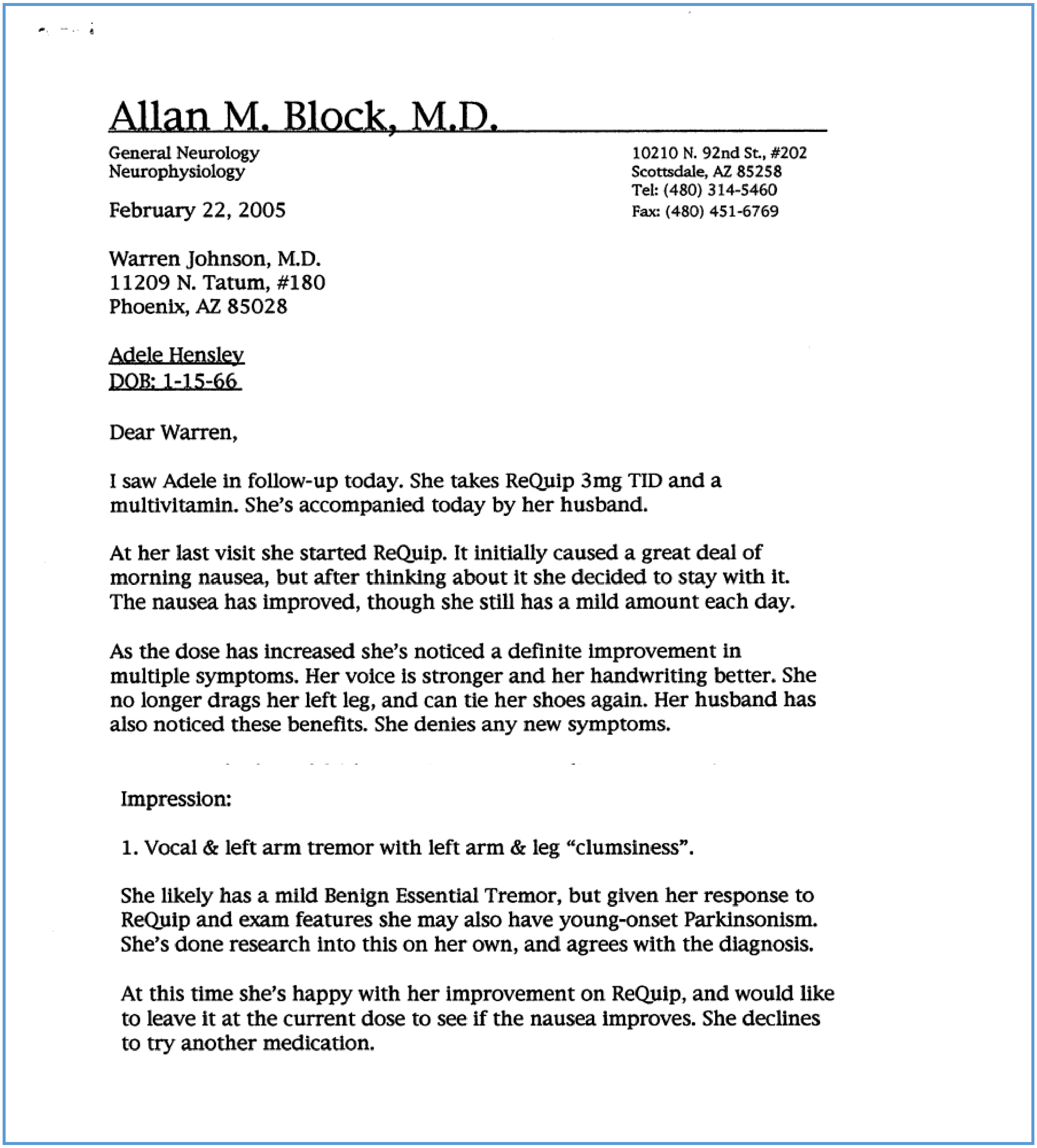
I. December 28, 2004

My doctor came around and sat lightly on the edge of his desk.
"I'm sorry. You have Parkinson's disease."
For almost four years, I had been trying to find out what was wrong so I could <u>fix</u> it.

Sorry. Some things can't be fixed.

I called my husband. I drove home.
A friend from church, a professor of nursing,
came over to answer questions and tell us what to expect.
You can't fix Parkinson's, but you <u>can</u> predict what is going to happen.

It is strange to know what is going to happen to you but not to have a schedule.
All the pamphlets said that you could expect ten good years.
They also said most people were diagnosed with Parkinson's around the age of 60.
I was 38. Did I have ten good years left, or nearly 30?



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February 22, 2005

Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

Adele Hensley
DOB: 1-15-66

Dear Warren,

I saw Adele in follow-up today. She takes ReQuip 3mg TID and a multivitamin. She's accompanied today by her husband.

At her last visit she started ReQuip. It initially caused a great deal of morning nausea, but after thinking about it she decided to stay with it. The nausea has improved, though she still has a mild amount each day.

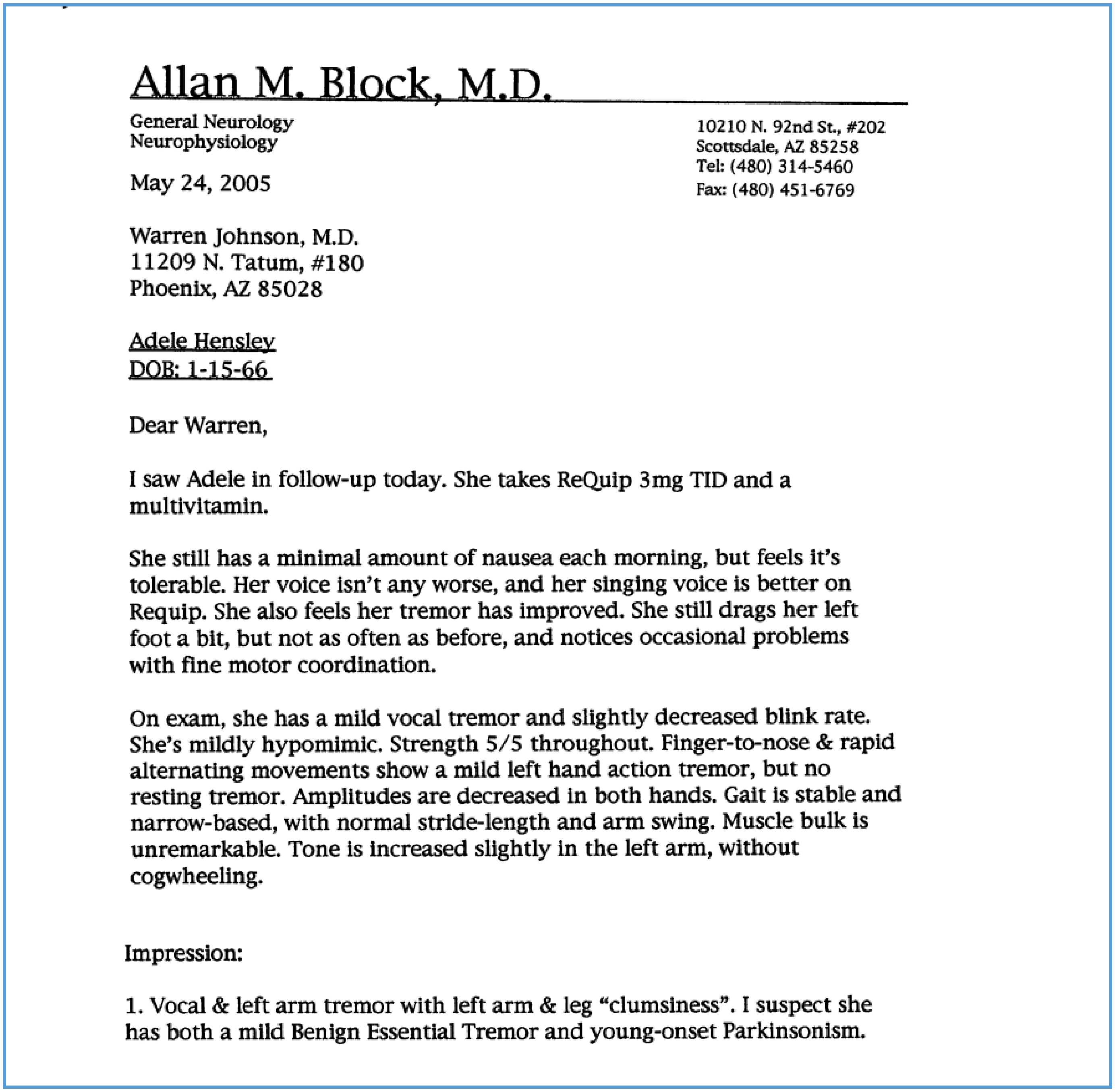
As the dose has increased she's noticed a definite improvement in multiple symptoms. Her voice is stronger and her handwriting better. She no longer drags her left leg, and can tie her shoes again. Her husband has also noticed these benefits. She denies any new symptoms.

Impression:

1. Vocal & left arm tremor with left arm & leg "clumsiness".

She likely has a mild Benign Essential Tremor, but given her response to ReQuip and exam features she may also have young-onset Parkinsonism. She's done research into this on her own, and agrees with the diagnosis.

At this time she's happy with her improvement on ReQuip, and would like to leave it at the current dose to see if the nausea improves. She declines to try another medication.



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May 24, 2005

Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

Adele Hensley
DOB: 1-15-66

Dear Warren,

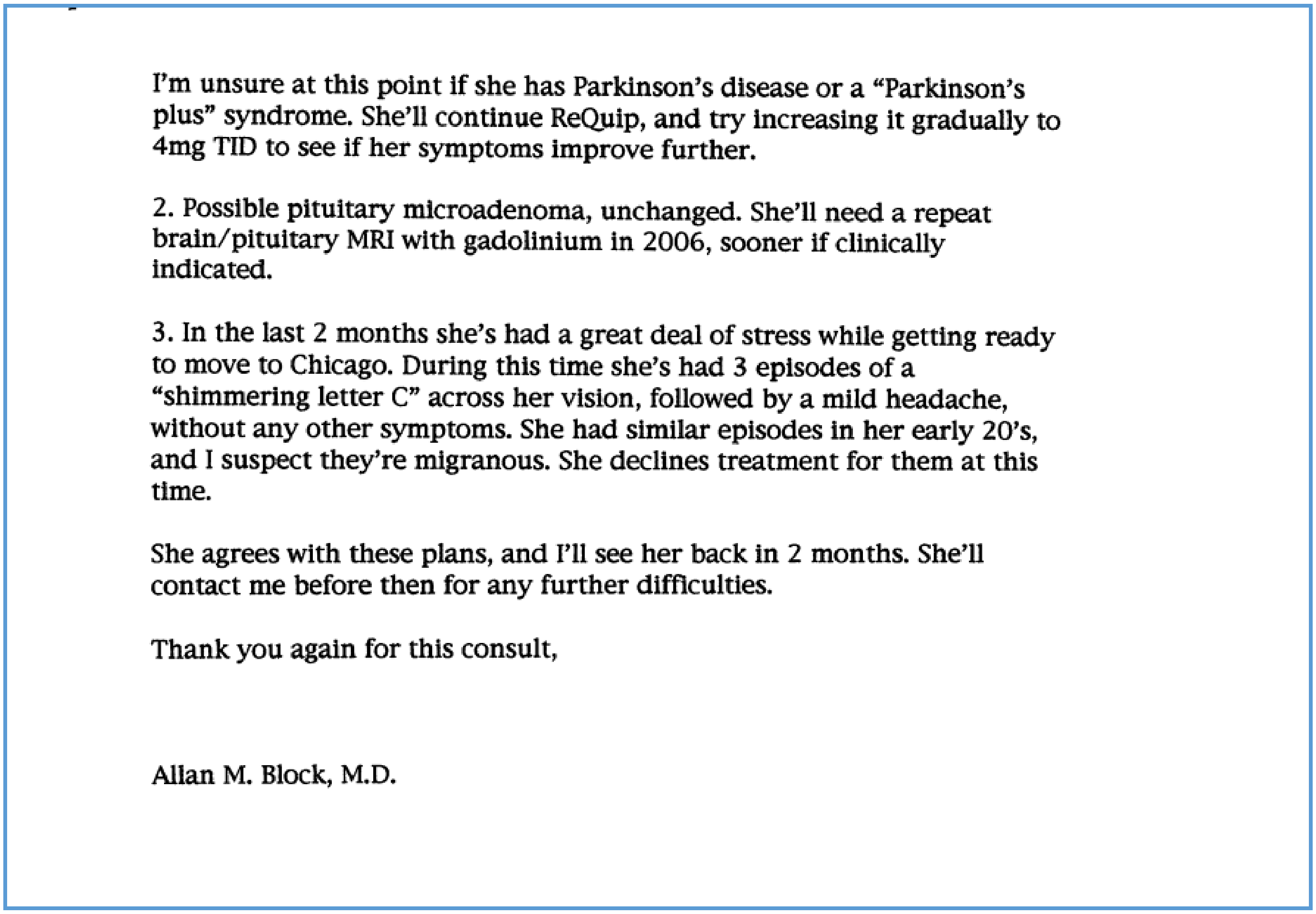
I saw Adele in follow-up today. She takes ReQuip 3mg TID and a multivitamin.

She still has a minimal amount of nausea each morning, but feels it's tolerable. Her voice isn't any worse, and her singing voice is better on Requip. She also feels her tremor has improved. She still drags her left foot a bit, but not as often as before, and notices occasional problems with fine motor coordination.

On exam, she has a mild vocal tremor and slightly decreased blink rate. She's mildly hypomimic. Strength 5/5 throughout. Finger-to-nose & rapid alternating movements show a mild left hand action tremor, but no resting tremor. Amplitudes are decreased in both hands. Gait is stable and narrow-based, with normal stride-length and arm swing. Muscle bulk is unremarkable. Tone is increased slightly in the left arm, without cogwheeling.

Impression:

1. Vocal & left arm tremor with left arm & leg "clumsiness". I suspect she has both a mild Benign Essential Tremor and young-onset Parkinsonism.



I'm unsure at this point if she has Parkinson's disease or a "Parkinson's plus" syndrome. She'll continue ReQuip, and try increasing it gradually to 4mg TID to see if her symptoms improve further.

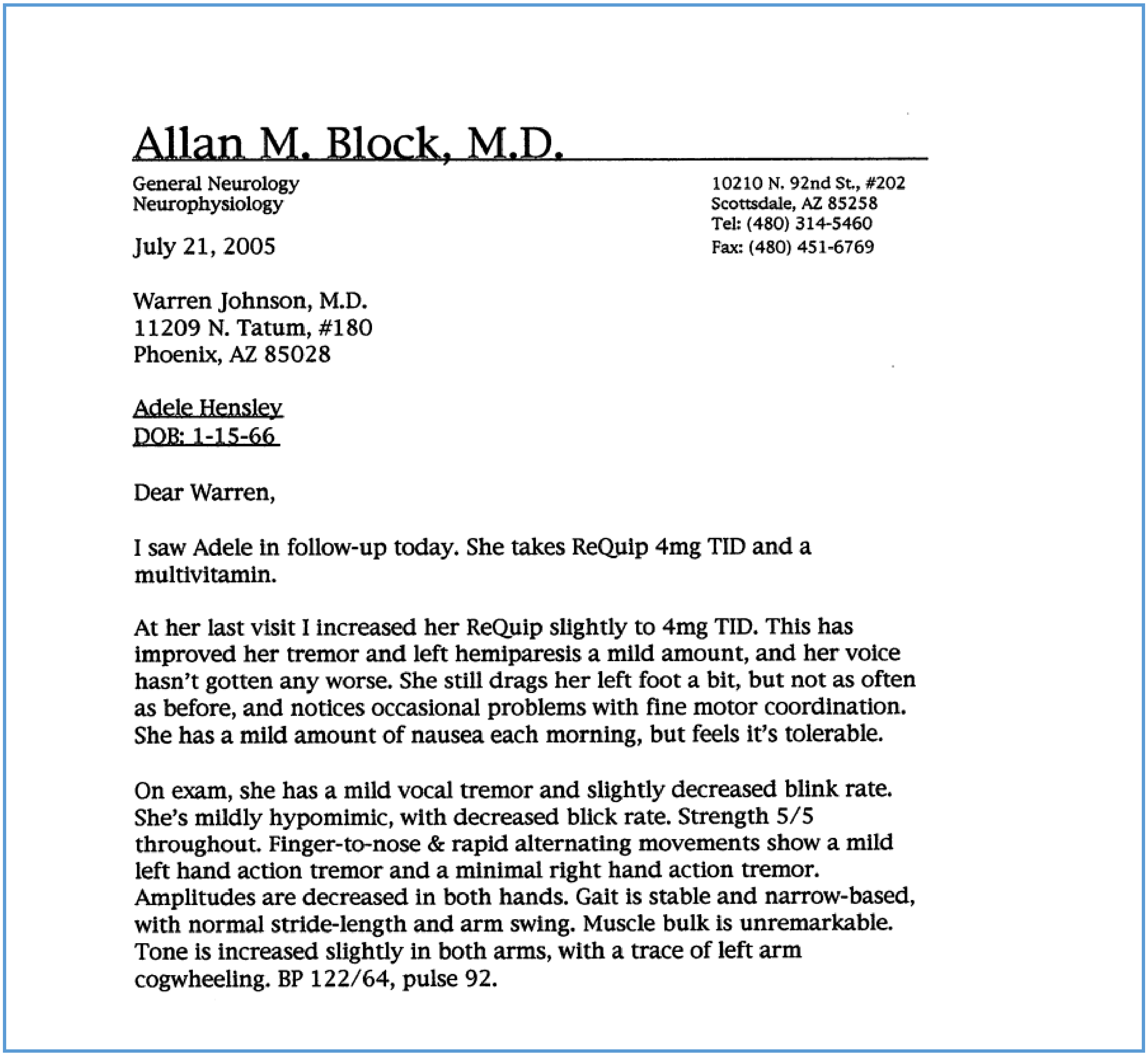
2. Possible pituitary microadenoma, unchanged. She'll need a repeat brain/pituitary MRI with gadolinium in 2006, sooner if clinically indicated.

3. In the last 2 months she's had a great deal of stress while getting ready to move to Chicago. During this time she's had 3 episodes of a "shimmering letter C" across her vision, followed by a mild headache, without any other symptoms. She had similar episodes in her early 20's, and I suspect they're migranous. She declines treatment for them at this time.

She agrees with these plans, and I'll see her back in 2 months. She'll contact me before then for any further difficulties.

Thank you again for this consult,

Allan M. Block, M.D.



Allan M. Block, M.D.

General Neurology
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Fax: (480) 451-6769

July 21, 2005

Warren Johnson, M.D.
11209 N. Tatum, #180
Phoenix, AZ 85028

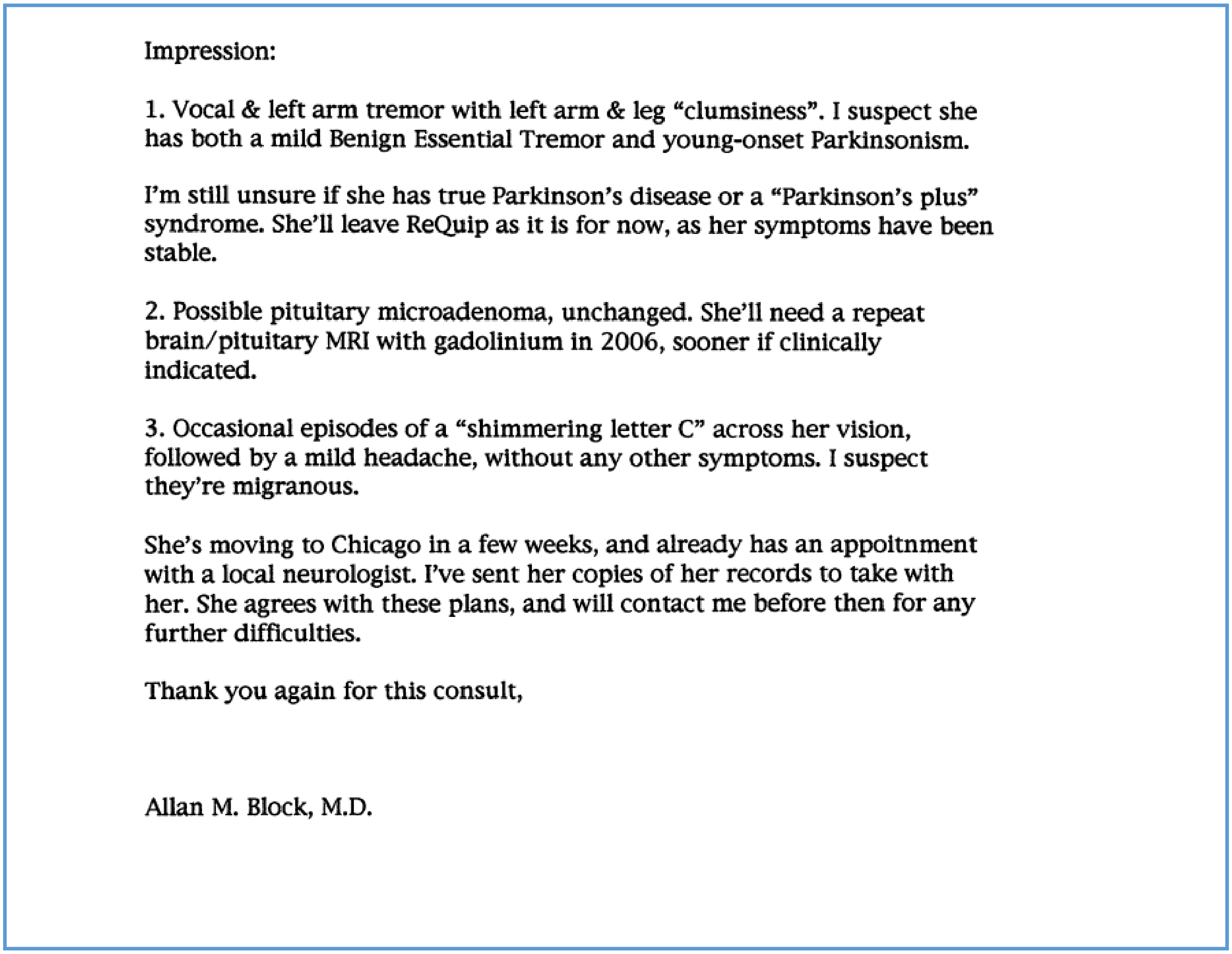
Adele Hensley
DOB: 1-15-66

Dear Warren,

I saw Adele in follow-up today. She takes ReQuip 4mg TID and a multivitamin.

At her last visit I increased her ReQuip slightly to 4mg TID. This has improved her tremor and left hemiparesis a mild amount, and her voice hasn't gotten any worse. She still drags her left foot a bit, but not as often as before, and notices occasional problems with fine motor coordination. She has a mild amount of nausea each morning, but feels it's tolerable.

On exam, she has a mild vocal tremor and slightly decreased blink rate. She's mildly hypomimic, with decreased blick rate. Strength 5/5 throughout. Finger-to-nose & rapid alternating movements show a mild left hand action tremor and a minimal right hand action tremor. Amplitudes are decreased in both hands. Gait is stable and narrow-based, with normal stride-length and arm swing. Muscle bulk is unremarkable. Tone is increased slightly in both arms, with a trace of left arm cogwheeling. BP 122/64, pulse 92.



Impression:

1. Vocal & left arm tremor with left arm & leg “clumsiness”. I suspect she has both a mild Benign Essential Tremor and young-onset Parkinsonism.

I’m still unsure if she has true Parkinson’s disease or a “Parkinson’s plus” syndrome. She’ll leave ReQuip as it is for now, as her symptoms have been stable.

2. Possible pituitary microadenoma, unchanged. She’ll need a repeat brain/pituitary MRI with gadolinium in 2006, sooner if clinically indicated.

3. Occasional episodes of a “shimmering letter C” across her vision, followed by a mild headache, without any other symptoms. I suspect they’re migranous.

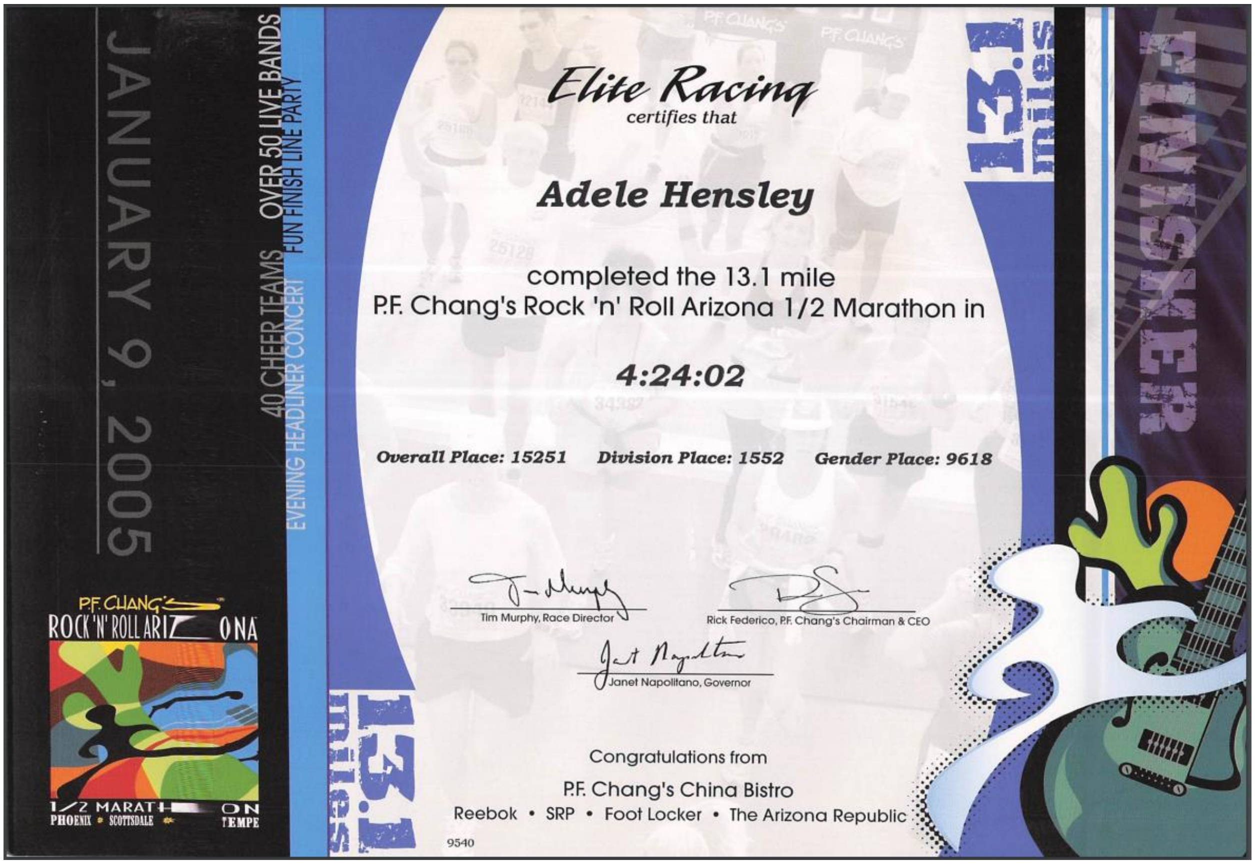
She’s moving to Chicago in a few weeks, and already has an appoitnment with a local neurologist. I’ve sent her copies of her records to take with her. She agrees with these plans, and will contact me before then for any further difficulties.

Thank you again for this consult,

Allan M. Block, M.D.

January 2005

As Adele had sought to protect her voice and find the cause of its decline, she had adopted a grain-free diet and had begun a program of intense walking, because she hoped exercise would benefit her entire body, but especially her voice. Adele got into the best physical shape since her days of playing soccer in junior high. Late in 2004 Adele's Aunt Becky said she wanted to come visit us in Phoenix and run the Rock 'n' Roll Half Marathon. She and Adele decided that instead of Becky running, they would walk the route together. And they did! I was so proud of Adele for working so hard to achieve this, but both of us were sad to know that it probably wouldn't help her voice much. We had no idea that Adele's exercise program was one of the best things she could be doing for her newly diagnosed Parkinson's.



JANUARY 9, 2005

40 CHEER TEAMS OVER 50 LIVE BANDS

EVENING HEADLINER CONCERT FUN FINISH LINE PARTY

P.F. CHANG'S ROCK 'N' ROLL ARIZONA 1/2 MARATHON
PHOENIX • SCOTTSDALE • TEMPE

13.1 miles

Elite Racing
certifies that

Adele Hensley

completed the 13.1 mile
P.F. Chang's Rock 'n' Roll Arizona 1/2 Marathon in

4:24:02

Overall Place: 15251 ***Division Place: 1552*** ***Gender Place: 9618***

Tim Murphy, Race Director

Rick Federico, P.F. Chang's Chairman & CEO

Janet Napolitano, Governor

Congratulations from
P.F. Chang's China Bistro
Reebok • SRP • Foot Locker • The Arizona Republic

9540

13.1 miles

FINISHER

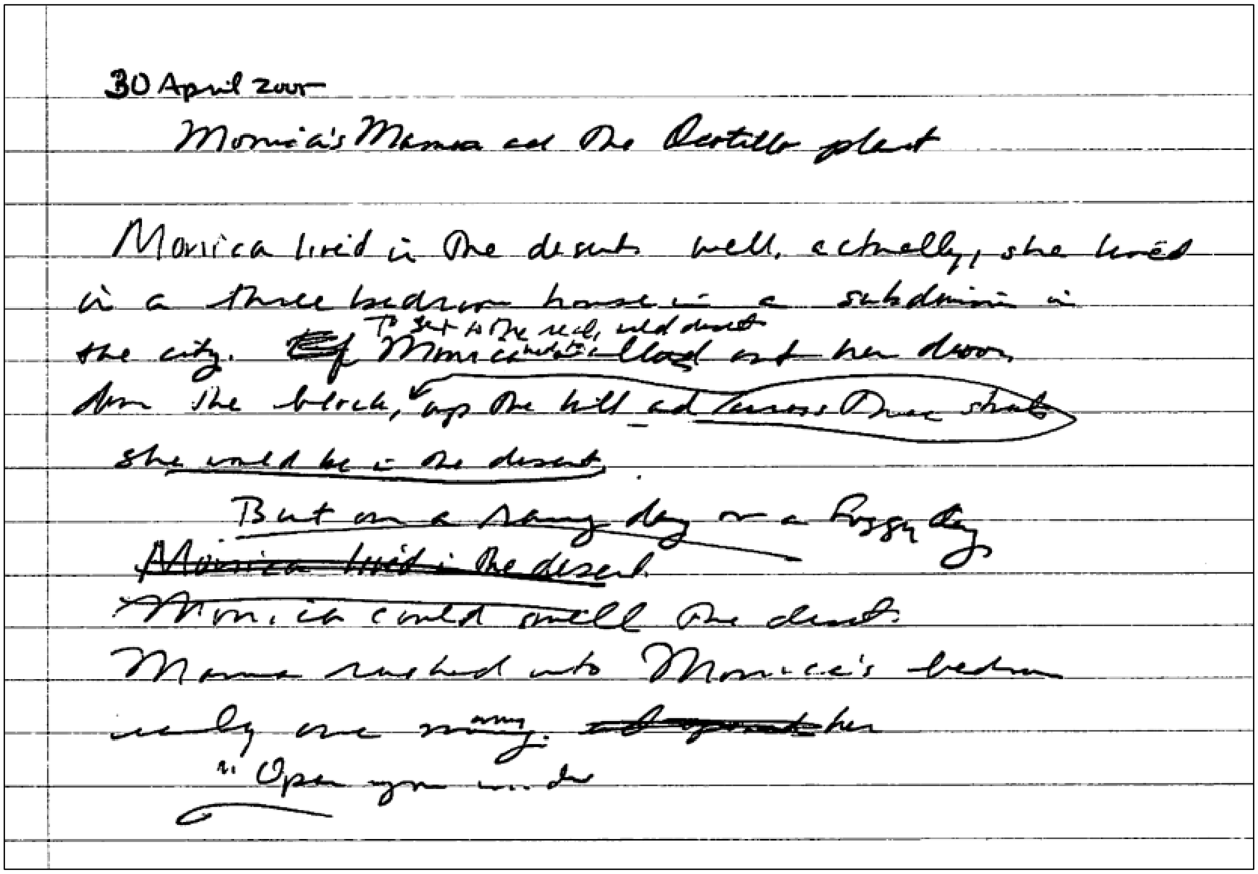
April 2005

Having been diagnosed for just a few months, Adele took me to our first Parkinson's-related event. I don't recall what organization sponsored it. I do recall the man at the Social Security Administration table asking us if we had any questions about qualifying for disability benefits, and Adele coming to tears as she answered him that she hoped she wouldn't have any questions for many years. (It turned out, she had six years left to work, before PD would end her last paid job.)

At that conference, I attended an information session that was aimed at family members and caregivers, with the request that Parkinson's patients not attend so that others were comfortable with speaking freely. Two participants in the panel were a woman and her grown son. Her husband had passed away after many years of battling PD. Her son talked about his childhood memories of helping his father tie his shoes and button his coat. Their take-home message was that if you have Young Onset Parkinson's, your kids are going to turn out fine. When I told Adele about the session, the tears flowed again – because her deepest concern was always for Clark.

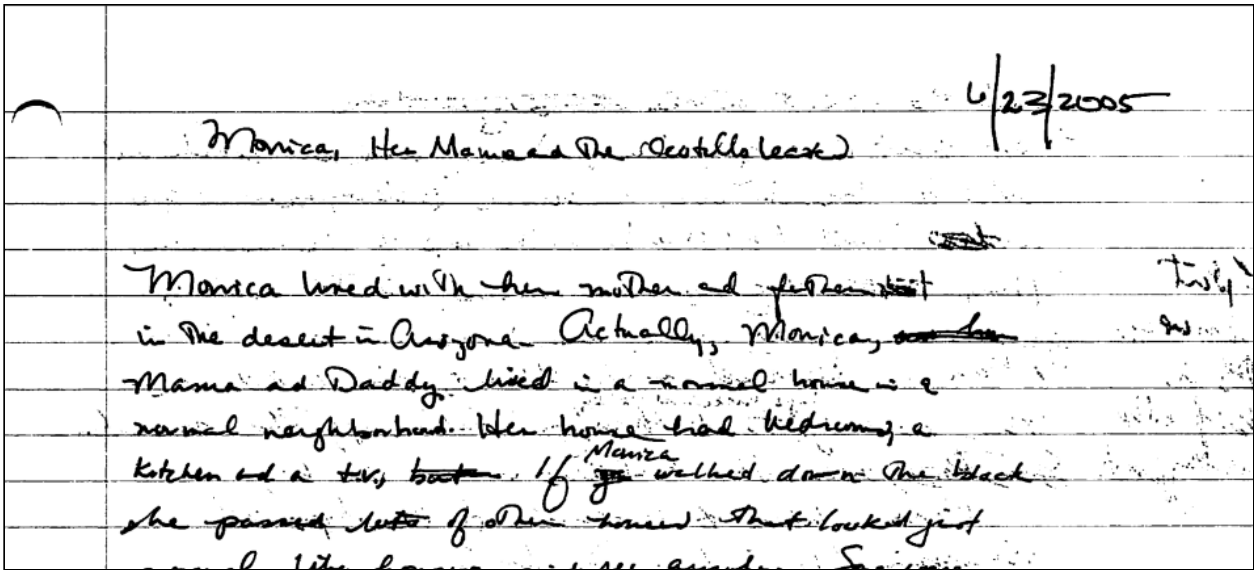
Would Clark be OK? How would she be able to be a good mother? Most people diagnosed with Parkinson's are over age 60, not parents of small children. Adele quickly discovered that there was nothing to help kids understand when a parent is diagnosed with such a degenerative disease.

I wrote the above paragraphs in 2023, based on my memory of that conference. I didn't know, didn't recall that this concern for Clark was germinating a story idea that would eventually become Adele's first self-published book. But just after I wrote about her concerns, deep in an old notebook, look what I found: Monica's Mama and the Ocotillo Plant.



30 April 2005
Monica's Mama and the Ocotillo plant

Monica lived in the desert. Well, actually, she lived
in a three bedroom house in a subdivision in
the city. ~~If~~ Monica would walk out her door,
To get to the real, wild desert
down the block, up the hill and across [illegible] Drive so that
she would be in the desert.
But on a rainy day or a foggy day
~~Monica lived in the desert.~~
Monica could smell the desert.
Mama rushed into Monica's bedroom
early one morning. ~~and [illegible]~~ her
"Open your window



6/23/2005
Monica, Her Mama and the Ocotillo [illegible]

Monica lived with her mother and father ~~[illegible]~~
in the desert in Arizona. Actually, Monica, ~~and her~~
Mama and Daddy lived in a normal house in a
normal neighborhood. Her house had bedrooms, a
kitchen and a t.v., ~~but~~. If ~~you~~ Monica walked down the block
she passed lots of other houses that looked just

Watch for it to grow…

May 2005

Sandy's memory of diagnoses.

Facing Our Fears

Adele called to tell me her devastating diagnoses of Young Onset Parkinson's Disease at the end of 2004. In that same phone call, I told her I had finally been diagnosed with Chronic Fatigue Syndrome. At the time I was functioning much worse than Adele, but we now knew that her health would decline for the rest of her life while my dysfunction would be sporadic. Our futures would be drastically altered in ways we neither expected nor liked. What on earth do you do in the face of such devastating news?

If you are Adele and me, you go to the Grand Canyon! On a cold morning in May of 2005, we woke up in our tent before dawn to welcome the sunrise over the Grand Canyon. Adele and I were in awe of its greatness and the spectacular nature of the moment as the sun beams broke over the horizon suddenly, then slowly illuminated the absurdly large canyon before us. I was humbled, feeling small compared to the grandeur before me. I treasure that moment with Adele, standing together in awe of the natural world, God's creation, imbued with a taste of Heaven. God who created this Grand Canyon, also knit me together in my mother's womb and knew every hair on my head. No matter what Adele's and my futures held, I knew with certainty we would not be outside of the reach of God.

Later that day as we hiked the rim, Adele spotted a large, black, gangly bird. As we saw another, and another, she explained to me the Condor was all but extinct, and great efforts had gone into making sure the species continued and flourished. We were witnessing their rebirth as they soared on the updrafts. It was almost unbelievable. I felt confident that with God all things were possible. No matter how our lives unfolded, God would be there with us.

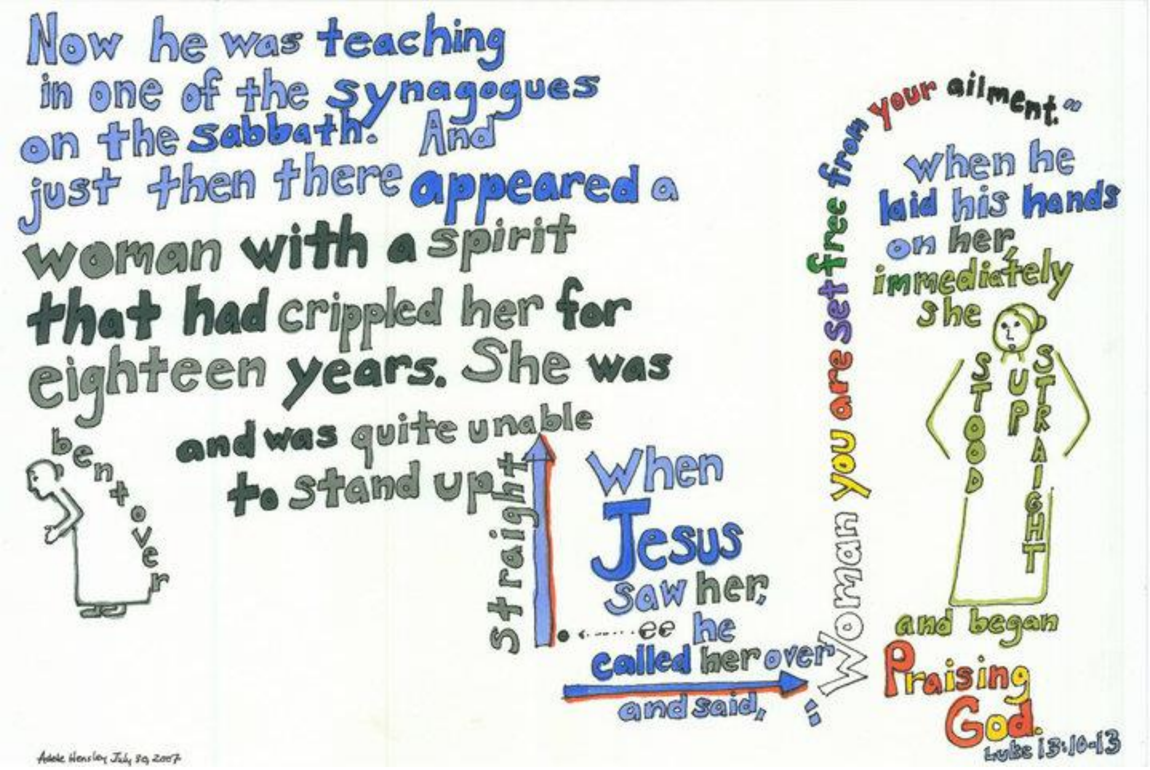
VI. City of Big Shoulders

August 2005

What started as my dream job in Arizona became a huge disappointment, and I just couldn't stay there. The college went bankrupt and was sold to predatory investors whose only mission was making money, regardless of educational goals or mission. So, in 2005 we migrated to the suburbs of Chicago where I found an excellent new job and where we braced ourselves for ice and snow. We didn't know what else might come our way, but a couple of things in Chicago went on to make a huge difference in our lives.

Our first year in Chicago Clark was in kindergarten, but when he started first grade Adele decided she wanted to apply for a job at the Presbytery of Chicago as the librarian for over 100 Presbyterian churches. I was apprehensive about her working in downtown Chicago, commuting every day by car or by train. I was also concerned about her slowly deteriorating health and whether she would be able to handle the stresses of a full-time job and being a mother. As it turned out, she was up the task for several years, and her work at the Presbytery meant she qualified for health insurance, retirement benefits, disability insurance, long-term care insurance, and death benefits. Adele worked there for about 4 years, but the financial benefits to us were huge; we would have been bankrupted by Parkinson's if it were not for the generous benefits of the Presbyterian Church U.S.A. As I write this in August of 2023, I'm about to receive Adele's final paycheck from the year of salary that is one of her death benefits. Adele's work is still paying for our house and helping with a retirement nest egg. I'm enormously grateful both to Adele and to Presbyterians.

At the Presbytery Adele attended a workshop called "Praying in Color" where she learned spiritual practices of combining art with meditation and prayer. She practiced two versions. In one practice, she would write the names of people or concerns, and then decorate and color each one while praying about them. The other practice was illustrating scripture. This hearkens back to the ancient practice of illumination of scripture. She did many of these, but the most iconic one for me is from one of the healing miracles of Jesus in Luke's gospel. Adele and I called this illustration "Bent-over Woman."



Given that Parkinson's affected Adele's posture and balance, how could she not see herself in this story? But Adele's faith had a very practical side to it…she believed that we are God's instruments to heal each other, and that we look for God's healing to be delivered in the hands of God's people. At Baylor, Adele had gotten very frustrated by a physician at the campus health center (known as the "Quack Shack") who diagnosed her with a viral infection and offered nothing more to treat it than to pray with her. She firmly believed that her health concerns needed evidence-based medicine and that prayer, in color or otherwise, was appropriate for healing her soul and giving her the strength to handle the challenges of Parkinson's Disease.

Spring 2006

In 2006 we started Clark in Taekwondo class. He took to it right away. After a few months, it was clear that he was getting bigger, stronger, faster, and more confident. His instructor, Master Dexter Grove, encouraged parents watching from the sidelines to join in. I didn't have a lot of confidence, but I agreed to give it a try. During my first couple of weeks of class, Master Grove and Master Tom Lennon both asked me if Adele would join, too. I explained that Adele had Parkinson's and both of them offered "So what?" kinds of answers. It made perfect sense to them that she should train for a black belt… so, just a few weeks after I started, she joined us! It was to become one of the most important experiences of her adult life.

March 2009

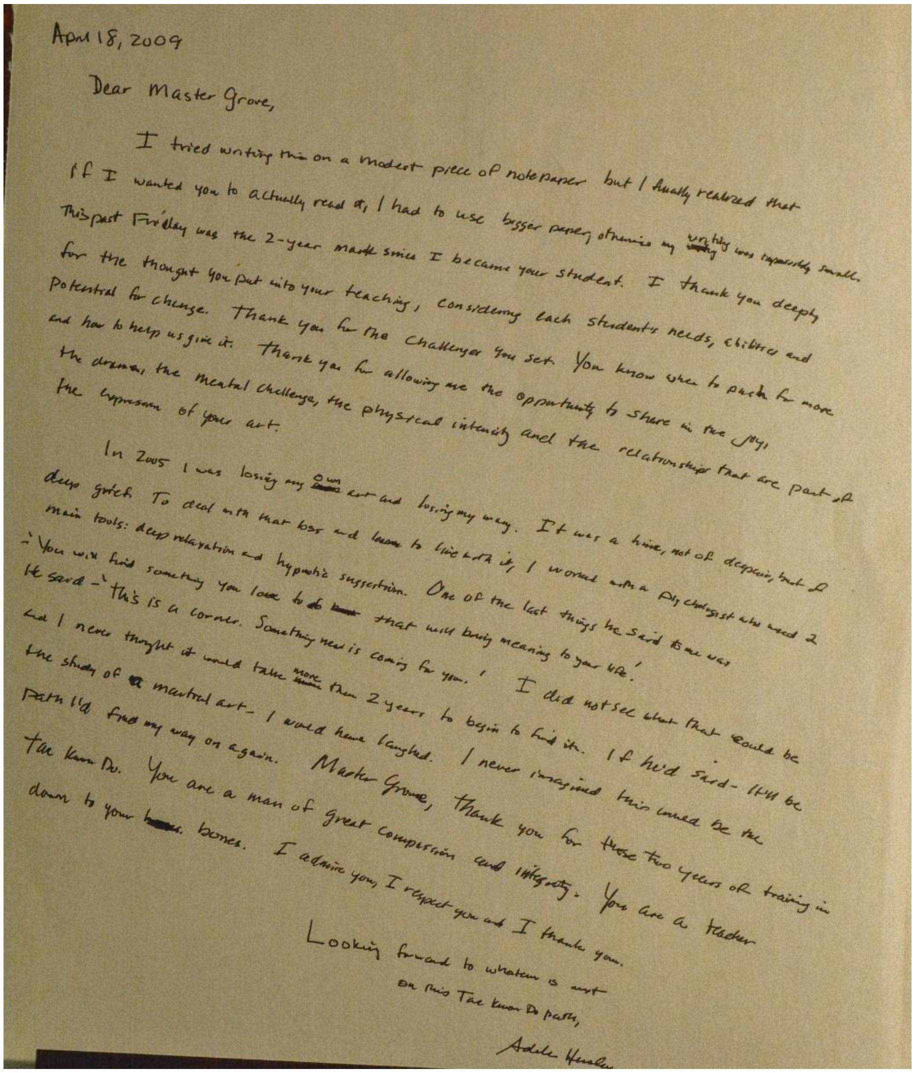
Drool

"Cats rule. Dogs drool...." the cat declares with withering disdain. It is an unanswerable insult. I mean, think about who drools. Babies drool so much, they wear bibs to keep their clothes dry. Pavlov's dog drooled automatically in response to a ringing bell. Mentally compromised people drool. And I drool. For years, it happened but only on rare occasions, then it happened every night, but only in my sleep, lately, though I find myself drooling in my office, in my kitchen, in front of people
and alone.

April 2009

If you go back and look closely at the Bent Over Woman above, and you know what to look for, you'll see it: The sequence of belts in our Taekwondo school were white, yellow, orange, purple, green, blue, red, and black!

April 18, 2009



April 18, 2009

Dear Master Grove,

I tried writing this on a modest piece of notepaper but I finally realized that if I wanted you to actually read it, I had to use bigger paper, otherwise my writing was rapidly smaller. This past Friday was the 2-year mark since I became your student. I thank you deeply for the thought you put into your teaching, considering each student's needs, abilities and potential for change. Thank you for the challenges you set. You know when to push for more and how to help us give it. Thank you for allowing me the opportunity to share in the joy, the drama, the mental challenge, the physical intensity and the relationships that are part of the expression of your art.

In 2005 I was losing my own art and losing my way. It was a time, not of despair, but of deep grief. To deal with that loss and learn to live with it, I worked with a psychologist who used 2 main tools: deep relaxation and hypnotic suggestion. One of the last things he said to me was "You will find something you love to do that will bring meaning to your life." He said – "This is a corner. Something new is coming for you." I did not see what that could be and I never thought it would take more than 2 years to begin to find it. If he'd said – It'll be the study of a martial art – I would have laughed. I never imagined this would be the path I'd find my way on again. Master Grove, thank you for these two years of training in Tae Kwon Do. You are a man of great compassion and integrity. You are a teacher down to your bones. I admire you, I respect you and I thank you.

Looking forward to whatever is next
on this Tae Kwon Do path,

Adele Hen

Dear Master Grove,

I tried writing this on a modest piece of notebook paper, but I finally realized that if I wanted you to actually read it, I had to use bigger paper. Otherwise, my writing was rapidly smaller. This past Friday was the two-year mark since I became your student. I thank you deeply for the thought you put into your teaching, considering each student's needs, abilities, and potential for change. Thank you for the challenge you set. You know when to push for more and how to help us give it. Thank you for allowing me the *opportunity to share in the joy, the drama, the mental challenge, the physical intensity, and the relationships that are part of the expression of your art.*

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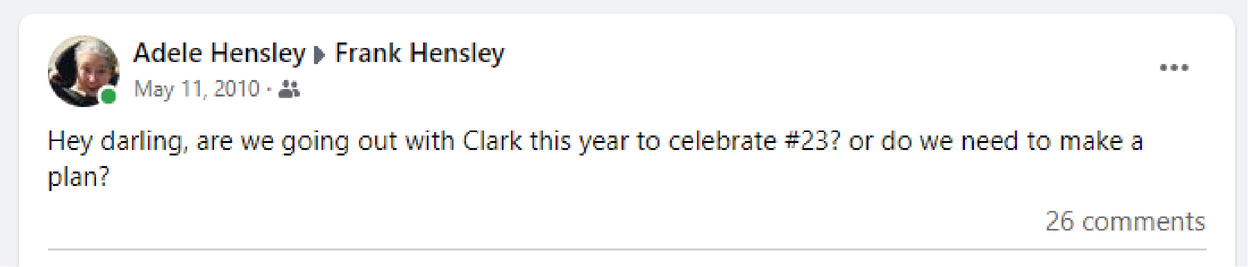
Looking forward to whatever is next on this taekwondo path,

Adele Hensley

May 2010



Adele Hensley ▸ Frank Hensley

May 11, 2010 ·

Hey darling, are we going out with Clark this year to celebrate #23? or do we need to make a plan?

26 comments

This kind of thing was so typical of Adele. Why wouldn't you include your child in your plans to celebrate a wedding anniversary? That was our default mode. On a few occasions, we actually got a babysitter and went out without him, but that was the exception, not the rule.

August 2010

Adele and I earned our Black Belts in Taekwondo! You can watch a video on Adele’s YouTube channel of Adele breaking a board during her test.

February 2011

Parkinson’s medications typically are fast-acting and short-acting. So, PD patients take medication several times per day, cycling through a rollercoaster of “on” and “off” periods, plagued by alternating symptoms and side effects.

Dear Frank, would you be able to call Dr. Kompoliti's office before noon and ask them to call me back this afternoon? If you can, please tell them that my off times have increased in duration and severity (1.5 hours is common, tears, labored breathing, extreme fatigue, increased urinary incontinence, troupe [trouble] *lifting my head are common off symptoms for me). Do they have any suggestions for what to do? Also Please tell them I am going to stop work this Friday and apply for disability through my employer.*

If you can't call, please let me know.

Delly

February 4, 2011

Effortless Movement--Lost and Found

Some children love to taste the world; everything they see goes straight into their mouths. My son rarely put anything in his mouth. Instead, when he was a little boy, he was endlessly fascinated by holes. Any round hole he saw, he’d stick his finger into it. You can be sure I put safety caps on every electrical outlet we encountered. He loved bookshelves. They have those little holes for the pins that support the shelves, and those holes are just the right size for exploring with baby fingers. Why did he put his finger into little holes again and again and again? He was training his brain. He was learning how long it takes to put a finger on a particular target and how much pressure is needed to achieve the slight “pop” of a finger coming out of a hole. Part of the work of being a baby is to repeat tasks that require planning and thought until they become effortless and can be done in an instant.

We employ this training technique throughout our growth and development. You might remember how hard to was to tie your shoes at first, or to bat a ball, or write your name in longhand. Most of us don’t remember learning to stand or to walk, but the method was the same. We practiced each basic skill until the *necessary movement, balance and timing were so ingrained in the brain and body that it became automatic. Sometimes, as we age, things happen that alter the relationships between movement, balance and timing. As our bodies change, our brains may not recognize that the formulas we taught them in early childhood no longer accurately describe the complex process of, say, walking without falling, rising from sitting, or swallowing saliva before it becomes drool. Everything is effortlessly automatic, until one day you fall, or drool, or cannot get up from a chair. You feel surprised, even shocked. You wonder what happened and why and whether it will happen again. Long before we could understand why, we each spent countless repetitions learning the perfect timing of our bodies. If the timing has changed, we need to relearn the timing.*

When I was 34, some skills that had been automatic became nearly impossible for me. I got a little worried and started to look for answers. When my skills continued to deteriorate and I could find no answers, I became deeply worried. After about five years of searching, I described to my neurologist a weird incident. A few days earlier, I had bent over to pick something up and had drooled on the carpet. He came around his desk and said, "I think you have Parkinson's Disease." Parkinson's Disease is a disease that unravels a person's known relationship between balance, timing and movement. Some cells deep in the brain in an area called the substantia nigra stop producing a neurotransmitter called dopamine. Without the regular production of dopamine, the brain starts to have trouble coordinating movement. A formerly smooth gait becomes a jerky foot-dragging limp with one arm bent at the elbow and tucked tight against the hip. Some movements become incredibly slow. A hand may start to shake. Those are the first threads to come loose. As the disease progresses, a person gradually loses effortlessness.

Few movements are automatic. A person experiencing Parkinson's can do almost anything if he or she can figure out how and if he or she can not care how long it takes. When I pay for something with a debit or credit card, part of my mind is figuring out how to get the card out of my wallet, swipe the card, and put it back. That same part knows about how long that usually takes someone. Another part of me watches how long it really takes. It is embarrassingly long. When Parkinson's is described, it is always like this: it is a progressive degenerative *neurological disorder, for which there are treatments but no cure. I do not dispute that, but I think that people with Parkinson's can retrain our brains for automatic movement by repetitively practicing particular movements over and over, just like we did as babies. We are slower and our balance has changed but if we can learn the new relationships, we can do new tasks, and old ones, too. I think this is why Tai Chi classes help protect people from falling. In Tai Chi you learn a set number of movements with an emphasis on balance and timing. You practice those same movements over and over. You retrain your brain. Many people with Parkinson's can hardly walk but love to dance. The rhythmic music provides a timing framework within which the brain can coordinate movement. The actions of a partner provide immediate signals for pre-learned movement responses. The dancing person does not have to figure out what to do. Dance flows, the movements are automatic.*

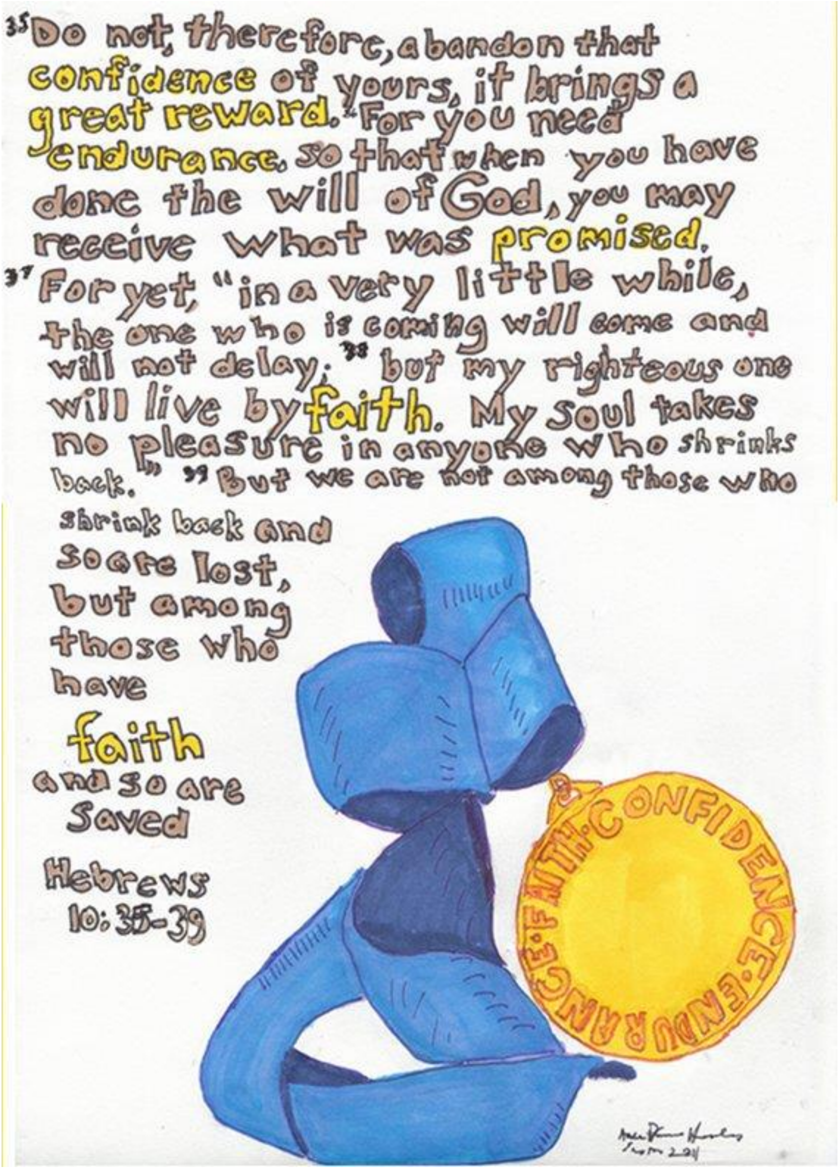
In 2007, when I was 41, I started studying Tae Kwon Do. Traditional Martial Arts train brains to relearn the coordination of timing, movement and balance. Certain motor skills, called fundamental movements, are drilled day after day so they can become automatic. Patterns of movement, called forms, are practiced hundreds of times, until they flow. Another kind of pre-learned movement pattern, called one-step sparring, is always performed in response to a signal from a partner. Because the sequences are preset, the emphasis of this type of training can be on timing and strength and flow, rather than on figuring out what to do. For me, the most important moment of my Tae Kwon Do training are those times when I am fully in the moment, moving without planning or analyzing, because these are movements I have trained my brain and body to do with timing and balance.

April 2011

A MRSA infection in her foot knocked Adele out of Tae Kwon Do for about a month… and regular vigorous exercise is essential for slowing the progression of Parkinson's disease.

This was an Easter Sunday I didn't think could work. My Grandma died yesterday, my pastor was leaving after today, and resting my foot to heal this staph infection has intensified the symptoms of my Parkinson's disease. I felt like I could give this Easter a miss, but I've been working on this scripture passage. One thing I can do while sitting with my foot up is color. It's for a friend I want to encourage.

I was working on it and I realized this is a message we all need--again and again: Do not abandon your Confidence. You will need Endurance. Do not shrink back, live by Faith.



[35] Do not, therefore, abandon that
confidence of yours, it brings a
great reward. [36] For you need
endurance, so that when you have
done the will of God, you may
receive what was promised.
[37] For yet, "in a very little while,
the one who is coming will come and
will not delay; [38] but my righteous one
will live by faith. My soul takes
no pleasure in anyone who shrinks
back." [39] But we are not among those who
shrink back and
so are lost,
but among
those who
have
faith
and so are
Saved

Hebrews
10:35-39

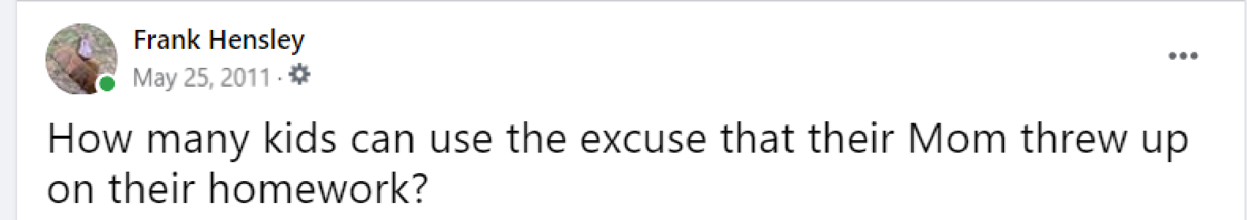
April 2011

Fiery red has mostly faded back to lurid pink,
and I can stumble without pain from bed to bathroom sink.
This staph infection's falling back and soon it will let go.
Until it does, my foot is up, and I miss Tae Kwon Do.

April 2011

Adele left her job with the Presbyterian Church USA, retiring on full disability. For the next 12 years, the PCUSA carried our family's health insurance with no premium. We paid deductibles and co-pays, but the Presbyterians spent at least half a million dollars on Adele's Parkinson's treatment. Jesus said, "Heal the sick" and the PCUSA did their best to try. We didn't end up in medical bankruptcy, by the grace of God and people who cared about taking care of others.

May 2011


Frank Hensley
May 25, 2011 ·

How many kids can use the excuse that their Mom threw up on their homework?

VII. Poetry and Motion

July 2011

We made a big move. To be closer to family, we uprooted from our sojourn in the Chicago suburbs and transplanted ourselves to Mississippi. Knowing that Adele's parents were just three hours away was a huge comfort for us, given the uncertainty of her health. And Clark would get much more grandparenting!

Change of Plans.

Decisions made with logic, sharp and clear,
Contribute to a certain frame of mind.
Expecting that a pattern will appear,
I am convinced I live by my design.

Every day in every situation,
I calendar and journal and make plans.
I know my future. Without hesitation,
When asked to do a task, I say, "I can."

But that was all before I learned the limit
Of how much I am really in command.
People, places, really every minute:
These are gifts that can't be summoned on demand.

The future wants planning but this is the deal:
The present needs focus. It's what is real.

Adele Pfrimmer Hensley

October 2011

Adele wrote this poem in October, but the incident came down in August, while I was sitting in my first faculty meeting at my new job at Mississippi College.

Strike.

Lightning hit the pine
and the house shivered.
The tree stood as straight
and tall as ever, but
the strike blasted
a strip of bark
and the delicate,
hidden, layers
of vascular tissue
right off the tree
and left a scar,
wood white,
that ran from
the treetop to
the ground.

I hoped it might recover,
but when a tree explodes
and parts of it land
thirty feet away,

the damage runs deeper than
just one scar.

The cicadas emerging from the roots
and leaving their nymphal existence behind

should have been a clue.
I still hoped, but then
the needles began to brown
and the tree was lost.
I thought that
was that.

I didn't realize that damage to one pine is
an opportunity for an epidemic.
Pine beetles flourish and begin to spread
from tree,   to tree,   to tree.
Aggressive action can keep a yard
from becoming the neighborhood's
ground
zero.

We
lost
three.

Moving to Mississippi meant lots of changes for all three of us. Adele and I always wanted Clark's life to be as normal as possible because we knew that Parkinson's Disease was going to leave its mark on his childhood as she got progressively worse. So, making him happy made us feel happy, as if we were holding Parkinson's at bay, if only a day at a time. Clark wanted a snake for his 11th birthday (and we both wanted a snake, too). So, Selena joined our family shortly after we moved to Mississippi.

You might expect the story to go like this: The new pet snake bites the child, and a mother's apprehension turns to emergency protectiveness, and the next day the snake is gone. But not at Adele's house, where, instead of an eviction, we got a poem.

New Relationship

The first day,

The boy made a motion like a puppet in front of the snake.

The snake bit him.

The boy learned that the snake needs some personal space. A boy's thumb is not so different from a mouse to a snake's heat-sensitive pits. The boy learned to give the snake a reassuring touch before lifting it from the tank.

The boy learned to keep his cool when faced with the unexpected. He learned that he could put the snake safely away, then take care of his own needs. "It wasn't her fault," he told his mother.

He learned that he could go back and work with the snake and build a relationship.

Now,

The boy holds the snake confidently, feeling it grip and release his forearm. He is starting to feel something like love for his snake.

The snake hangs on to the boy with its coils, stretching to taste the air in every corner it can reach while anchored to the boy. It is learning that the boy's hands are gentle. The boy is warm.

The snake is content.

Lots of friendships are built on less.

November 2011

“Go. Have a fun day. I'll be fine."

"But you don't have a Loretta Davenport[14] *here that you can call. I guess you could call the church."*

"I could but I won't have to."

That was the last bit of conversation Frank and I had this morning. An hour later, I sent the dog out to bring in the paper, but the paper wasn't here. Instead Gryff stalked over to trade growls with one of our neighbor's wandering dogs, who had come into our yard. I took Gryff by the collar. He complied but he was walking faster than I was and at the top of the driveway, I fell flat on my front. Gryff went to sniff a tree. After a while he came back and went into the house like I told him to. He cried while I crawled slowly to a chair and stood back up. That was before 7:30 a.m. Everything's fine now. Let's see what the rest of today holds...

December 2011

I began Physical Therapy, work on conditioning, balance, and strength has yielded fine motor improvements, overall quality of life is much better.

December 19, 2011

What does romance look like when you’ve been married to a nerdy nature lover for almost 25 years?

This:

---

[14] A dear friend in Chicago.

Squirrel Tree Frog

A frog with skin of spring grass green
was resting by the window screen.
It sat immobile, quite composed,
with folded legs and tucked in toes,
and like some waxen household god,
it watched each step we people trod.
The tree frog waited silent, still,
passive, stolid, fixed, until
the evening air's humidity
unlocked its limbs and set it free.
Each night it left the bathhouse wall,
and right away began to call.
The call from one male's creamy throat
would split the night. Its pleading note
was echoed by each frog who heard
and was equipped to spread the word.
The longing heard in each frog's voice,
revealed his need to be the choice.
of one dear frog to be his wife.
He'd go back to his double life
tomorrow, on the bathhouse wall.
Tonight, though, was his night to call.

If I had known to listen well
to what this frog had words to tell,
I could have had my fortune told
by wee green frogs with voices bold.
The call they use to call the rain
is quite close to my husband's name.
These frogs are loud from tree or bank
and what they say is, "Frank, Frank, Frank."

December 20, 2011

Adele loved me. Adele loved nature. And Adele loved her family and her friends. I don’t know which friend inspired this poem, but they clearly inspired Adele. So, whoever you are, thank you.

A Daffodil in Snow

My friend saw a daffodil,
pushing through the snow,
occupying winter
with last spring's sunshine's glow.

Daffodil collected light
and stored it in the ground.
The bulb drew no attention,
dry and hard and round.

Autumn's nights grew longer
the sun seemed far away.
Winter's cold then gripped the land.
It seemed like it would stay.

The daffodil knew better.
It could defy the cold.
It had sunshine's energy
waiting to unfold.

My friend's life is like this.
This fall's been hard, so dark.
As she finds the hope she stored,
her life regains its spark.

She showed us all the picture
of a daffodil in ice.
This is what she wants to be.
I thought, "The picture's nice."

But as I've thought about it,
I think she's found a key
that opens up the health
and hope she needs to be set free.

My friend is like the daffodil.
Her reserves of strength are vast.
She pushed herself through dark and snow,
and has emerged at last.

Her friendship and her spirit
shine like that golden flower,
She's fueling her rebuilding
using her remembered power.

December 2011

Disagreements with health insurance companies...got one bill reduced from $148 to $11. But I had to concede defeat on another bill...$422 because the doc wrote two diagnosis codes in a certain order - reversing the order would have made insurance pay, but the hospital denied the appeal. Oh, well...

February 24, 2012

Rain isn't the only thing that falls. Adele fell, smashing the toilet tank as she went down. She ended up on the bathroom floor, soaking wet, with water gushing from the broken tank filler valve. And she couldn't get the valve turned off. She wasn't hurt – just humiliated and demoralized by her deteriorating independence.

We always had "rules." Not enforceable rules…just principles for harmonious living. When we were dating, if I teased Adele about something, she'd often respond "That's not in the rules!" She also regularly threatened to take me "back to the boyfriend store!" for a refund, if I broke "the rules." Well, Adele's loss of balance eventually resulted in two house rules:

1. No falling.
2. No falling, dammit!

Both of us tried our best to make sure we didn't break these rules, but Adele became a repeat offender. As her condition worsened, she had progressively less control over this, so her caregivers and I were the guilty ones.

March 2012

For many people, a mouse in their kitchen is distressing, scary, or disgusting. Especially if there are mouse droppings involved. But if you're a nature lover, former "rat madame," and poet, a mouse is a muse.

Sleight-of-Hand (?)

Dropping me a greeting
as it ran across my floor,

the mouse took cover
under my chair

and disappeared.

April 2012

Quick personality diagnostic:
It is six in the morning, your wife/mother/friend is distressed but knows if she can focus on something besides how she feels, she can get through the emotional turbulence. She says, "Talk to me, please."
Is your response A. to glibly invite her into your internal discussion?
Or is your response B. to freeze and become silent inside as well as out?
If you answered A, you are probably an extrovert.
If you answer B, you are probably an introvert.
Try this test with your loved ones. You may be surprised. Even people who are extremely verbal, may be introverts. Or maybe the truth is that Everyone but me is an introvert at 6 am?

I have no idea whom she is talking about.

May 2012

Adele wrote me these three poems as gifts for our 25th wedding anniversary:

May 16

May Sixteenth will make Twenty-five years
of your life and my life being our life together.

There are, after all these places and all this time,
so many things we can remember.
So many more have all but vanished
from either my mind or yours.
If it weren't for you, I would know less
than half the story of this relationship.

Even if I forgot everything we had ever done
these touchstones will never fade:
the touch of your hand that keeps me grounded,
the touch of your eyes, when you smile,
the scent of your neck when you kiss me,
the gentleness and strength of your voice.

Loving you has been more than a tally of places in events
(How many? The cities, the houses, the friends).
It has been a lifelong study of the knowledge
of you
down to your
deepest self.
Knowing you
delights
my heart.

Regrets only

We said we would and so we do
stay married. Oh but if we knew
the things this life would put us through,
would we still have said "I do?"
You would have? Good. I would have, too.

Your Love is Good Medicine

I see you and I feel a smile
rise up from my throat,
or maybe from my lungs.
Wherever it originates,
the smile you bring to my face
helps me breathe more easily.
Even the space between my outer toes
feels more lively when I see you.

I hear you and a sense of peace
settles around my emotional neighborhood,
like the snow that settles around Chicago in January.
It fills up the crevices and ditches
and puts everything on level ground.

I feel your touch and I relax.
It is like meditation.
My heart beat is strong and regular.
My shoulders drop back to their proper level.
I can stand up straighter, or I finally
can fall to sleep.

We celebrated our "silver" anniversary with matching silver rings adorned with lizards. Lizards? Yes!

We had developed a tradition when we lived in Phoenix, Arizona, where each year on our wedding anniversary in May, we would drive up to the summit in South Mountain Park to look at lizards. South Mountain is the only place in the world where you can find Common Chuckwallas (*Sauromalus ater*) with orange tails. We talked about getting matching Chuckwalla tattoos, but we aren't tattoo people, so we never did.

Chuckwalla photo By Randy Babb, copyright 2023. Used with permission.

Remind me, Which one is the Lizard Anniversary?

Paper
Silver
Textiles
I used to read the list
In that square pocket calendar
I got each year
from the greeting card store.
I wondered who would give someone a gift made of paper
as a reminder of their wedding day.

Now, though, I am giving you gifts made of electrons,
poems written without pen or pencil or even paper.
I wonder if we could persuade the greeting card store to write a new list,
Where the gifts you give have more to do with things you love or love to do.

Our list would have
books
snakes,
frogs,
turtles,
the desert,
Karate,
Montana,
the beach,
Tae Kwon Do,
Labrador retrievers,
Birds,
Bugs,
Flowers,
Clark,
Bicycles,
Laughter,
Camping,
And this year,
our 25th,
would be called
the Lizard Anniversary

Adele Pfrimmer Hensley
20 April 2012

And here's what I wrote to her:

Happy 25th Anniversary, Adele!
Thank you for: love, Clark, Great Blue Herons, taekwondo, church Christmas programs, Clark, Spinach Madeline, Montana, Pfrimmers, trying to rescue a

Wood Duck duckling that got separated from its mother, trying to rescue a beaver that got pinned under a tree it cut down, successfully rescuing box turtles and a mud snake off roads, Clark, going birding with no binoculars, watching a family of otters cross the road in front of us, driving to the summit of a volcano in New Mexico, camping in the Rocky Mountains with pathetic sleeping bags and two warm Labrador retrievers, shooting in the basement, shooting in the attic, and shooting off the front porch of the North 40, tubing down Ichetucknee Springs, visiting Natural Bridge and Kartchner Caverns, Clark, the Lincoln Memorial, the Air and Space Museum, Clark, Shedd Aquarium, Audubon Zoo, Bluebonnet Swamp, Paynes Prairie, the Bison Range, BaptoMethspeterian churches, Duke Forest, the Craigs, the Polaskis, the Pyles, The Revs. West, blue water at Destin, Cabbage Key, Wupatki, Coconino Christmas trees, The Flying Burrito, Clark, Red Meadow, Saltwater Cowboy's, green corn tamales, Cottonwood Creek, Zoolights, The White Tanks, Clark, SREL, the Field Museum, Dr. Who, the front steps of South Russell Hall, Cedar Waxwings, mud-themed 4th birthday party, Paul Simon's Graceland, camping in the Ford Ranger, poems, NPR, the Broadway version of The Lion King, fireworks, bat netting, Wasp Automotive, Clark, picking saguaro fruit, sequoia trees, monsoon on the Maricopa road, Bernalee's pool, Chiricahua field trips, Navy Pier and the Chicago Air Show, Moody Memorial Library, and so very much more! And don't forget counting chuckwallas on our anniversaries!
I love you!

June 2012

> After a physical therapy session, Adele wrote in her journal:
> *Itsy Bitsy Spider movement Worked!*

August 2, 2012

Adele fell face down in our driveway. It scared Clark pretty badly. It scared me, too, but I didn’t let them know that.

August 3, 2012

When I had to choose a quote for the yearbook my senior year of high school, I picked "You can't fall off the floor."

Well, you can't but the real question to ask yourself when you are face to face with a hard piece of pavement is, how are you going to get yourself up? Sometimes you need to rest and make sure you are not broken. Sometimes you need to hop right up and face whatever knocked you down. Sometimes you need to roll to the side to avoid being trampled.

Twenty-nine years later, I think my senior quote for the middle age annual should be "You can get back up off the floor. Then what are you going to do?"

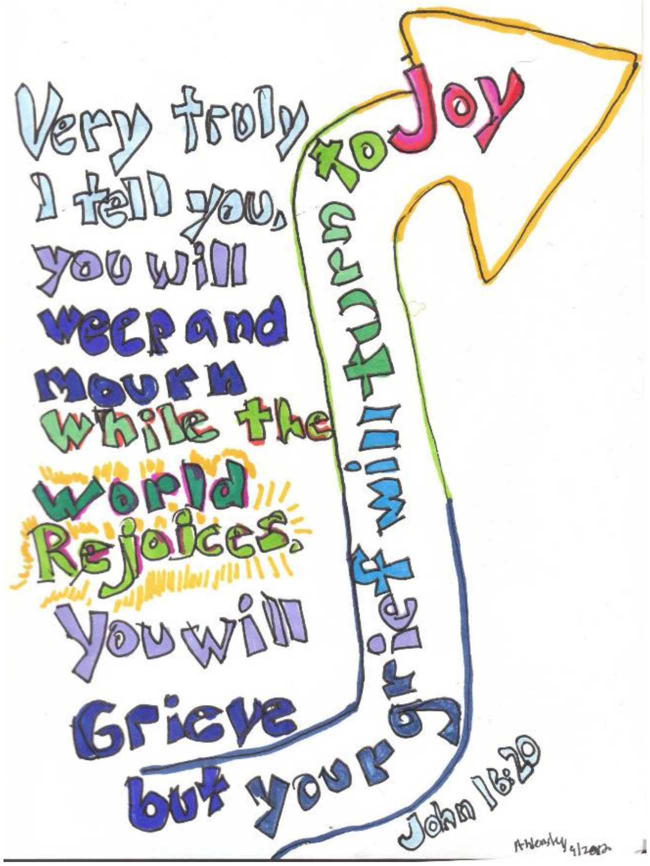
It took more than a week for the bruises to heal. Adele posted selfies to Facebook every day:

August 22, 2012

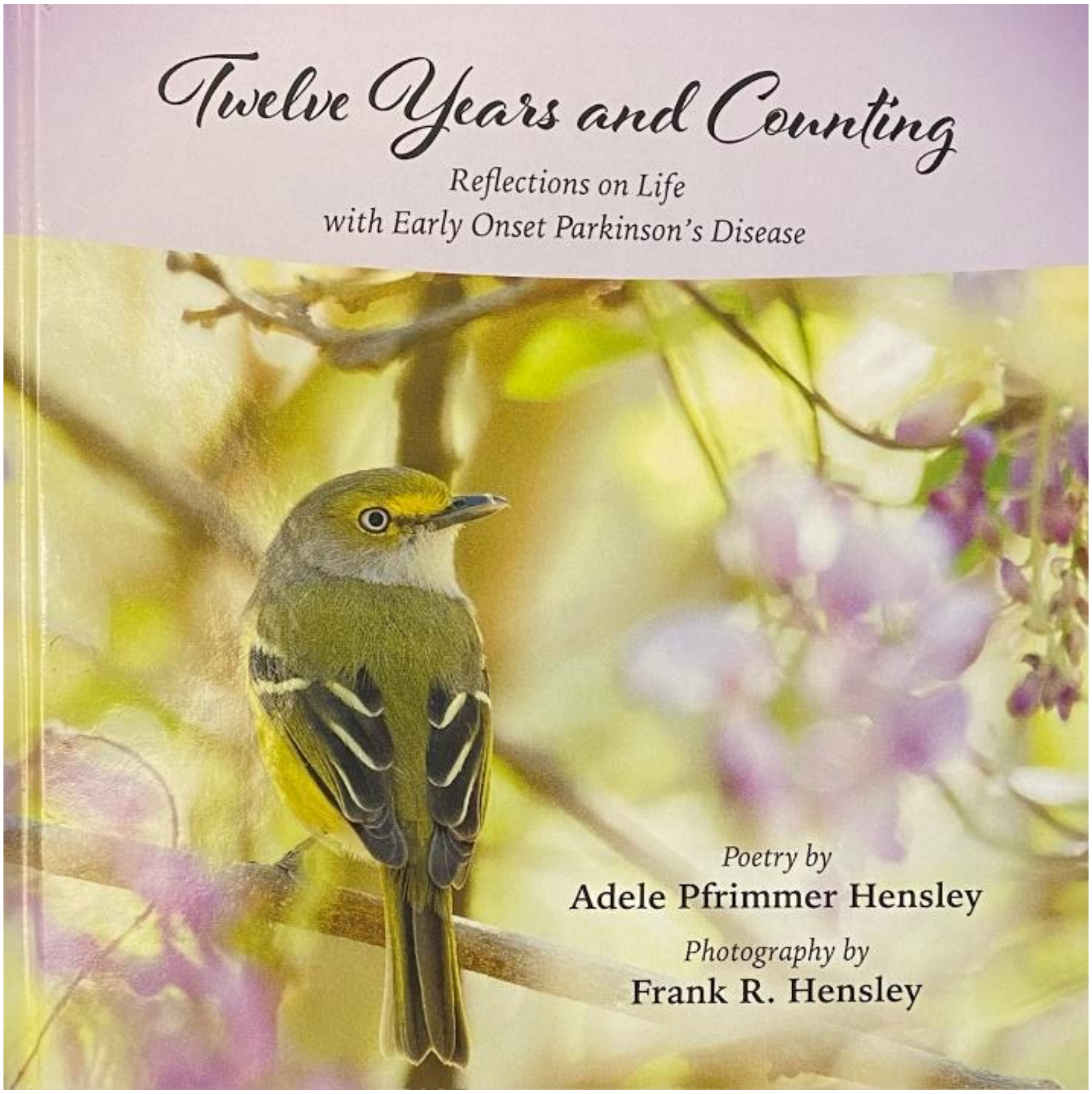
August 22, 2010: tested for first degree blackbelt in Tae Kwon Do in Midlothian, Illinois
August 22, 2011: began study of Shotokan karate in Clinton, Mississippi
August 22, 2012: I wonder what this day will hold in my study of the Martial Arts?

August 22, 2012

This is what I have been working on this week following my praying in color class at church. There are times when troubles seem endless. This reminds us that they are not.



Adele spent a lot of 2012 Praying in Color and writing poetry, much of it about life with Parkinson's Disease, many of which she published in her book Twelve Years and Counting.



Twelve Years and Counting
Reflections on Life
with Early Onset Parkinson's Disease

Poetry by
Adele Pfrimmer Hensley
Photography by
Frank R. Hensley

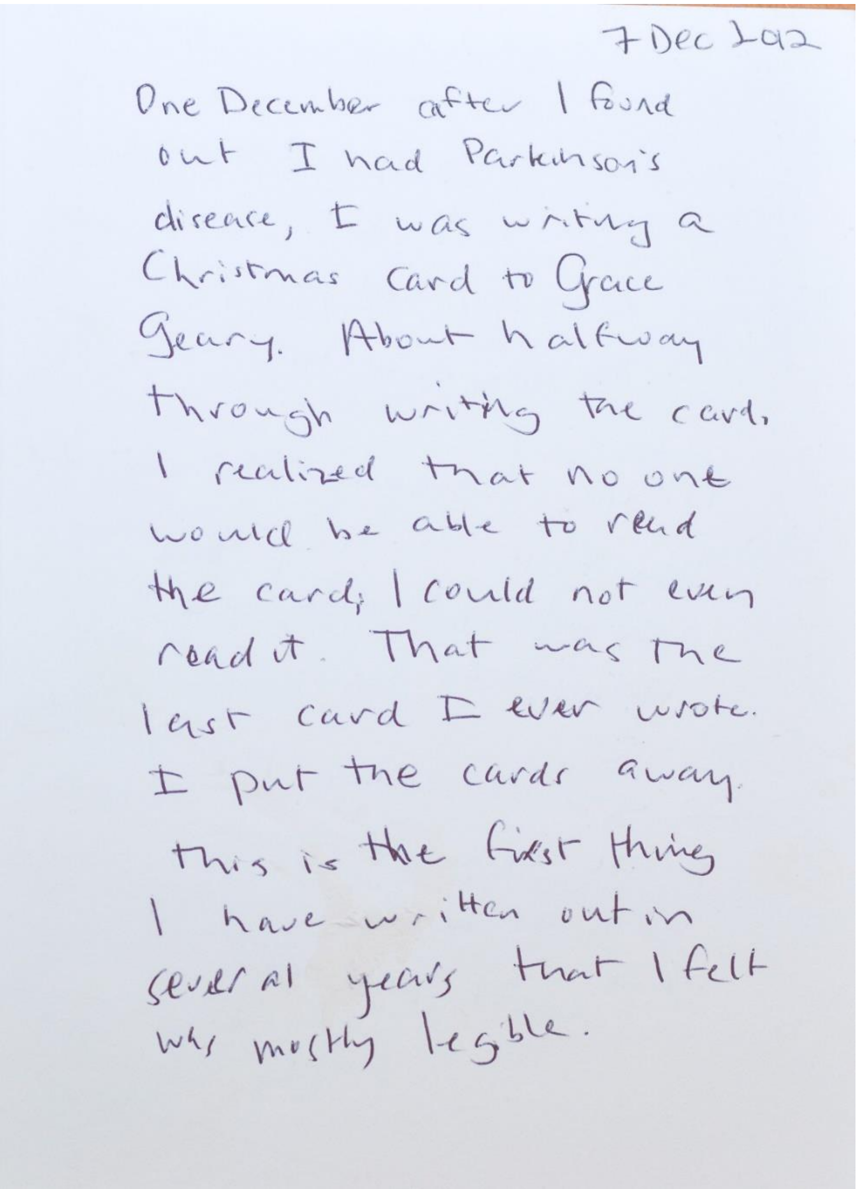
For some unknown reason in 2012, I decided to try my hand at Parkinson’s poetry, too. Just once. I’m not the wordsmith she was, and when I tried to be clever, I was obscure instead, so it would probably help you to know that in the Harry Potter books there’s a background character named Pansy Parkinson. I never titled the poem and didn’t share it, largely because I didn’t want to disappoint my mother by using a bad word.

I am alarmed at her need
for mind-altering drugs
so, I rise and pour her elixir.
I count out the mg. of brain function
and I am scared.

Am I a Pansy?
That's just a fictitious witch, but this
Parkinson's an unrelenting bitch
so, I count out her mg. of brain function
and I am scared that I can't help her.

She needs the drugs
to swallow the drugs.
A catch-22 in her throat. But if she can
choke down the mg. of brain function
it will slap that bitch, and for a
switch she'll be able to swallow
Parkinson's for a few hours
and I won't have to be so scared.

December 2012



7 Dec 2012

One December after I found
out I had Parkinson's
disease, I was writing a
Christmas card to Grace
Geary. About halfway
through writing the card,
I realized that no one
would be able to read
the card; I could not even
read it. That was the
last card I ever wrote.
I put the cards away.
this is the first thing
I have written out in
several years that I felt
was mostly legible.

One December after I found out I had Parkinson's Disease, I was writing a Christmas card to Grace G. About halfway through writing the card I realized that no one would be able to read the card. I could not even read it. That was the last card I ever wrote. I put the cards away. This is the first thing I have written out in several years that I felt was mostly legible.

VIII. DBS[15]

December 8, 2012

> *Today is the eighth anniversary of the day I was diagnosed with Parkinson's disease.*
> *After almost four years of knowing "something" was wrong, it seemed like a relief to know what it was. That was the last time Parkinson' s was in any way a relief.*
>
> *At first, my symptoms were not so bad. The drugs were a different story. Every day as I lay in my bed recovering from my Requip[16]-induced hangover, trying desperately to not throw up, I would say that this must be what people on chemotherapy feel like. That the best treatment for the illness was no different from a poison but enduring the drugs offered some hope of better health.*
> *Parkinson's has not enriched my life. It has systematically nibbled away at it. Imagine taking a tablecloth and trimming it down until only a doily is left. It still could protect a table but not completely and not as well.*
>
> *The changes I notice the most are the changes in things I thought were non-negotiable. Daily showers? Hair washing? Too tiring.*
> *A little saliva running down my chin? Not such a big deal but I will try to wipe it up before it gets my shirt wet, if my medicines are not too off.*

---

[15] Deep Brain Stimulation is a surgical procedure where wires are inserted into deep regions of the brain and electricity is continuously delivered by a pacemaker-like implant in the chest, to control neurological symptoms.

[16] Requip is a Parkinson's medication categorized as a dopamine agonist. This class of drugs is notorious for unpleasant side-effects such as vivid dreams, and compulsive eating, hypersexuality, and compulsive gambling. Some patients respond very favorably, but dopamine agonists have destroyed many marriages and retirement nest eggs, too.

I have changed my clothes in every kind of public restroom imaginable.

I don't cook very often. When I do, it is more like heating things up. My husband cleans our home, washes our clothes, cooks our meals, does our shopping.

If it were not for him, for his efforts, our family would crumble. I used to direct the children's Christmas program at church. The last time, my husband pointed out that when I would agree to do something, the consequence was that he would have to do it too, so I could get through it. That was a sobering picture of my new reality. My competent multitasking problem-solving personality no longer existed.

I have to spend significant time exercising, and my personal hygiene takes way too much time. My main contribution to our family life is taking care of myself so my husband and son don't have to do MORE of that than they already do.

On January 8, I will have the first part of a unilateral DBS surgery. I hope it makes a difference, at least in the duration and extent of my wearing-off time.

I hope that what it will do is give my family and me time and space to turn more outward and less inward. To be honest, when you ALWAYS have to think about how far you are from the nearest restroom and whether you can get your pants down quickly enough once you get there, you don't really have much attention or energy left for serving others.

Maybe this will let me weave paper strips through the holes in my doily until it becomes at least a placemat.

Brain surgery to weave a placemat. Now there's an analogy I bet her neurosurgeon has never heard. There's a quote attributed to Japanese actress Tamlyn Tomita: "If I am more fortunate than others, I need to build a longer table not a taller fence." I don't know if that was Adele's inspiration for the analogy, but the spirit is the same. Adele was a longer-table person through and through. Deep Brain Stimulation surgery was about relieving symptoms of Parkinson's Disease, but that wasn't the end unto itself. Adele had holes bored into her skull and wires jammed deep in her brain because she wanted to get back what Parkinson's took away… and that meant her ability to set a table to welcome and serve others.

December 2012

> *The Last Class?*
>
> *I don't know yet but tonight may have been my last martial arts class. I know, I know. I am not good at karate. I have so much trouble standing equally on both feet that there are days when I feel like I have a gravity deficit disorder. Instead of my feet pushing firmly against the earth, I often feel them skittering away, disrupting my balance, marring my kata. But one of the wonderful things about karate is that it has an expectation that you will work hard and do your best. Even with my flaws, karate is so good for me. It makes me work hard. It uses both sides of my body. It challenges me to try things using one leg standing balance. It challenges my memory. It forces me to build muscular memory. It makes me move swiftly. It makes me realize that I am strong.*
>
> *Next week is Christmas. The week after is New Year's Day. The next two Tuesdays are my two surgeries. After that I will need to watch out for my wires and my pacemaker. They can't take a blow. I don't know if I can really train and protect the hardware. I will have to see.*

I want this deep brain stimulation. I am eager to see what it can help me do. I think it could even improve my karate. Unless it cannot. So, tonight I am full of hope but a little sad. Martial arts are something I started a couple of years AFTER I was diagnosed with Parkinson's. Tae Kwon Do and Shotokan Karate have made me a different person than I was going to be without them. They have emphasized aspects of character that I demonstrated but had never articulated and never emphasized. They have also given me a way to strengthen the function of new motor neurons, even as Parkinson's has stripped old abilities away.

I hope I am not done but if I am, I will always be grateful.

Actually, after her first DBS surgery, Adele had to use a walker for a few weeks, but she worked hard at physical therapy and by June she went back to one karate class the week before her second DBS surgery. When she stepped out onto the dojo floor, the class gave her a round of applause. Unfortunately, that triumphal return proved to be her very last martial arts class. After her second DBS surgery, she was never able to walk safely without a walker again.

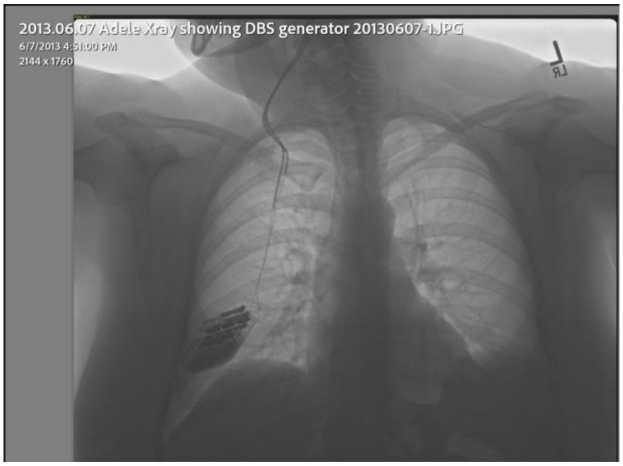
2013

Adele had her first Deep Brain Stimulator (DBS) implanted in January of 2013, on the right side of her brain, to help control Parkinson's symptoms on the left side of her body. A few days later, the programmable pacemaker was implanted in her upper right breast, and after a week of healing we returned to New Orleans to have the Neurologist turn it on and begin programming it. Clark got to be the one to push the ON button.

I should explain a bit of the procedure, so you'll follow Adele's account of it a little better. They begin by shaving the patient's head and then installing screws into the skull. These screws serve two purposes. One is that they anchor the head to a steel frame called a "halo" during surgery, so that nothing moves while the neurosurgeon is placing electrodes deep in the brain. But the screws are called "fiducials" because they serve as trustworthy points of reference. So, after the screws are in place, the patient undergoes both a CT scan and a brain MRI. Because the fiducials don't move, the neurosurgery team can combine the CT and MRI data to produce an intricate map of the brain, and to chart a course from the scalp to the target area, avoiding major blood vessels and minimizing any risks of injury. DBS surgery for Parkinson's patients can target either of two brain areas, the *globus pallidus* (GP) or the subthalamic nucleus (STN), depending on the patient's symptoms. For Adele, the STN was where they put the electrodes. The electrodes record the brain's electricity as they go in, and the neurology team knows what to look for and listen for to find the distinctive electrical pattern of each brain region as the electrode passes through. You might also need to know that Medtronic is the company that makes the stimulator, that Sinemet is the main drug that PD patients take to relieve their symptoms, and a stylet is a piercing tool that surgeons use to guide the insertion of tubes and wires. Also, Dr. Lee was a neurosurgery fellow, and Dr. Lea was a movement-disorder neurologist.

Adele, just before DBS, January 7, 2013.

Frank Hensley
It's only Jan 7th and Adele has already met her health insurance deductible and out-of-pocket limit. Do we celebrate?



This is a corrected version of my status from this morning. Whew! They said you could have some confusion after a DBS insertion. They did not say that you could accidentally paste the same material into your essay three times. Oops. This version should only have one copy of each idea.

Mrs. Hensley, what is it like to have brain surgery? What do you mean you were awake?!!
~~~~~~~~
My first brain surgery. 1/8/2013
Adele Pfrimmer Hensley

The surgery went well but it was long. I had to stop taking my Parkinson's drugs 12 hours before the surgery. By the time we began, it had already been 14 hours and I was pretty uncomfortable. The first surgery was done under sedation but really. I do not remember it at all. The second surgery, they had to keep me less sedated, so I could talk and participate during the electrode placement. So there I lay in the cold, cold OR, a kind woman gave me heated blankets and all of a sudden the anesthesiologist gave me something that melted my tension away. My hips softened and relaxed into the bed. My legs stopped twitching. I felt sleepy. I could hear everything but

I could not look unless someone addressed me and said 'Adele, Open your eyes.' Dr. Smith and another surgeon, Dr. Lee, began preparing to operate. They turned on some sort of heated air-filled system of plastic bags called a" bear hugger" and started a giant construction. I couldn't see everything but there was a metal tubing framework that reminded me of putting up a tent right around my head. There was a bank of computers, monitors and speakers to one side. The anesthesiologist was at a workstation near my feet. They put a layer of plastic coated with something sticky, sticky side down onto my bald head.

When it was all prepared, Dr. Smith made some sort of puncture through my skin into my bone. I know Master Grove always said not to punch an opponent's skull unless you want a broken hand, but I never appreciated the strength of the bones in the skull nearly enough. They really are a bulwark against invasion of the brain. Here were two strong men intent on breaking in and equipped with a complete tool kit, and it took them two separate assaults to make the tunnel into the brain. They said, a lot of pressure and i felt like my head was being shaken by a jackhammer. No pain, just a powerful vibration. Finally they were in. All the people who had been clustered in groups around the room chatting came over and went to work.

The recording process was difficult. Because I have not got a lot of tremor, they had to back off my sedation so that my rigidity could be apparent. Dr. Smith coached Dr. Lee through the calibration between the map and my fiducials. Then through the insertion of the recording electrode. Dr Lea, my neurologist, stood on my left so she could talk to me and see the computers over my shoulder. The speaker crackled. That is the sound of your brain, she said. Then the crackling was overlain with a low frequency electronic hum. The interference was not something they could localize and turn off. They got to the proper depth. Dr. Lea and the Medtronic rep would demonstrate the equipment's effects on my rigidity. That would show proper placement.

Dr. Lea asked me to raise my left hand and open and close it fast. Then she adjusted the degree of stimulation and asked me what I felt? I felt electrical currents in my left hand. Then it vanished. We tried two more times on three different depths. The results were the same.

The team stepped to the side to discuss the next steps. Meanwhile, I was stressed physically and psychologically. My hips were completely rigid again, my legs were going in and out of dystonia. Then my shoulders started to tense. I began to cry. I said, somebody please help me and Kolby, who had fitted me with warm blankets came and held my hand. She leaned in close and whispered, "Think of the songs that made you feel better when you were a little girl." I could not think of a single one. I did think, Amy is in the waiting room, maybe she could come in and sing...Naah. They teased that if I didn't think of something, Dr. Smith would have to sing. He politely declined. Oh, he does operations not opera? I asked.

Eventually, Dr. Lea was there she said she knew I was terribly uncomfortable but this was our shot. I heard Dr. Smith notice that the stylet was on the floor. How long would it take to sterilize it? The technician answered 10 minutes. I thought I could not stand ten more minutes. I cried more. Then I heard Jerry the rep from Medtronic say he had another one. Dr. Smith asked what was wrong with me, was I just emotional ? Dr. Lea said nothing was wrong with me except that I needed about three Sinemet. The anesthesiologist rubbed my hand, rubbed my foot and was very comforting. When I thanked them all, he said hey, it's our job. Then I remember someone saying something about a power strip. My interpretation was that the power strip had been the source of the interference. Dr. Lea and Dr. Rand watched me and listened. Suddenly , everyone's' eyes lit up. They could hear the STN. Dr. Lea asked me to raise up my hand and open and close it fast. I did and she said that's it. Dr. Rand agreed. I looked at her and asked what was different, how did she know? She smiled and said we hit it. I didn't perceive a change but she did. She said it would be a few more minutes and they could make me more comfortable. They did. Thank you, sweet anaesthesia!

I must have faded into sleep. The next thing I knew, a crackling sound ripped through the air. Then my bald head was being scrubbed roughly and thoroughly by someone who meant business. The person paid special attention to the places the screws had been hurting since the day before. I noticed that the screws must be out. Then Dr. Smith, the determined scrubber, tucked my head into the crook of his arm cleaned it off one more time and began to bandage my head. He taped it securely and said They need to see both eyebrows. I could hardly wake up. The anaesthesiologist wheeled me to the recovery room. His supervisor asked him how it went. He said it had been successful they had been particularly pleased with one particular thing that my brain couldn't understand. The head of brain anaesthesiology said that was good. This had just been their second such surgery and the first one had only gone so- so.

I got to the recovery room and I could not stand being without any dopamine any more. I became agitated, moving around, totally uncomfortable. By now it was well after 10 am and my last med had been at 6 pm the night before. I begged the nurse to get my husband, who had my parkinson's medicine. She thought I must be in pain to be so agitated. No I am not in pain I just really need my parkinson's medicine, I told her. Frank and Clark came back to the recovery room. Frank said Dr. Lea had said to take me my medicine, ask if he could give it to me and if they said no, give it anyway.

He did. It took awhile to get to my bran. The recovery room nurses asked the anaesthesiologist for something to make me more comfortable. I had to go for one more catscan. By the time i had been wheeled down the hall, my discomfort had been calmed by levodopa and ativan, and I was zonked out again.

My sisters, Amy and Anne, and my Dad were all on the ninth floor when we arrived. I napped. I held my father's two fingers, just like when I was a little girl, and slept.

A few days later...

DBS activation and Initial Programming Day

The night before my appointment, I skipped both of the long acting pills I take at night. I took a bedtime stalevo. I slept pretty well and woke for the day at 3:45 am.

All morning, as I moved further away from my most recent drugs, I grew more anxious, experienced more dystonia and slowly saw my gait deteriorate. I finally reached a point where I dragged my left foot completely and if I tried to hurry, say, to the bathroom, I could feel my feet going slower than the walker and the whole thing threatening to come apart. By the time we began my appointment, nearly 11:30 I had had trouble making it to the bathroom, trouble changing my clothing, and Frank tells me I also was having trouble with executive function (this was because I went into a bathroom with no phone). As you can see, Parkinson's is far more than a disorder of movement. Sometimes it feels like a disorder of your very being. My mother met us at the neurology clinic.

When we saw Dr. Lea, she asked Clark if he would like to turn my generator on. She introduced some equipment and taught me how to check the on/off status of the device and the battery levels. Clark put the switch on top of the generator and turned it on.

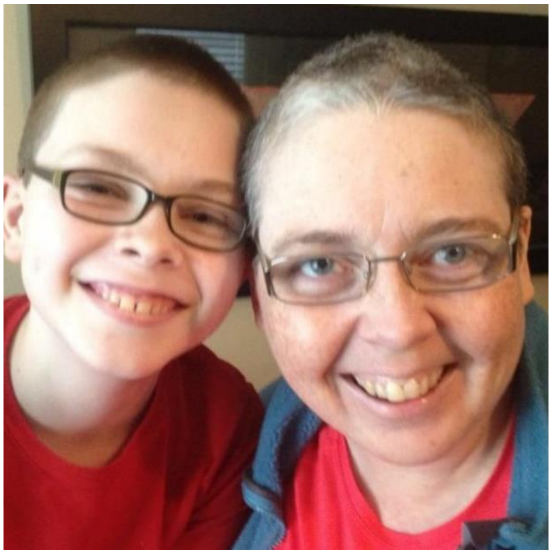
Dr. Lea told me she was going to test each of the four electrodes and see what the worst was that each would do so we would never have to do that again.

At different times, I felt tingling, muscle tension and discomfort , but a little while after turning the DBS on and trying some settings, I felt calm and normal. Maybe not perfect but restored to myself. Dr Lea said she had been hoping it would have more of an effect on my leg than my arm. It really seemed to be the case.

Nothing seemed to be the deep dark secret. So when Dr. Lea wrapped up, she said she was leaving my DBS on with generic low settings for all four electrodes. She said we would learn more from me living with it awhile than by me sitting by her while she pressed buttons. She said I should take my medicine and go. I asked if I should stay in case of intolerable side effects. She said not today. The settings are too weak to be problematic but next time I come, in two weeks, I should plan on it.

When I left her office I could almost not walk. Now that I am out of the car and my medicines are working well, I can tell that my left hand is more agile than my right. I can tell that is easier to take a big, Non-dragging step with my left, and I haven't had to change my pants since Clark turned this DBS on.

I am kind of glad for the rough morning, because it confirms that this is a real thing, that it is not the result of overmedication or imagination, and that it merits such a drastic response. Plus as long as I have this DBS I will never be completely that OFF again.



Clark and I didn't shave our heads in solidarity, but he did opt for a super short cut a month later…

Once she had regrown it enough, it was time for a playful hair adventure. She enlisted me rather than spend money on a professional job, and I hadn't ever done anything like this, so she ended up with a most amateur haircut. (It didn't help matters that she had to struggle to hold her head still because her DBS did not eliminate the dyskinesia caused by her Sinemet.) Six months later, after her second surgery, I got to do it again. I think the second one came out better, but I can't find any remaining pictures of it, so the first draft will have to do…

I only wish I had positioned it at a jaunty angle!

April 2013

Sandy’s memory:

Adele’s Artistic Adventures

Once Adele, Frank, and Clark moved to Clinton, Mississippi, in 2011, they welcomed me into their home quite often! I remember an afternoon of artwork with Adele when I stayed with her for a couple of days around 2013, while Frank took his students on a field trip and Clark was away. We started out with Adele showing me how to make pen and ink drawings using repeated parallel lines and waves. I really enjoyed being creative in that way, but it did not meet well with Adele’s tremor. So, she brought out her paint markers and played with color. She was working on an illustration of blackberries for her current book project. I suggested a technique using several colors for shading and outlining the color in black. These blackberries made it to page 5 of Face It: Making Peace with Fear. As we drew and colored and talked, Adele helped me make peace with some challenges in my own life. Our adventures were different now, but adventures just the same. That day was an adventure in creativity.

May 2013

Adele Hensley

May 16, 2013 · Clinton, MS ·

My Thursday blog post for P.A.N.D.A. is about the ways my amazing husband has helped me this year after my DBS surgery. Happy Anniversary, Frank!

PARKINSONPANDA.ORG

http://www.parkinsonpanda.org/1/post/2013/05/thursday-thoughts-when-is-a-caregiver-a-superhero-is-th

Today is the 26th Anniversary of my marriage to Frank Hensley. We met when I was 17, Frank was 18 and we had never even heard the words Parkinson's Disease much less had we ever imagined the ways in which something we were strangers to would come to shape the third decade of our marriage and beyond.

Our life together has been a cheery one. We have been best friends for almost thirty years. We each know the other as well as we know ourselves. We have now been married to each other longer than we were alive before we married. You might say that we are known quantities to each other. Except this year we learned that we are not.

In January, I had a series of surgeries to install and support the function of a Deep Brain Stimulator (DBS) on the right side of my brain. This pacemaker-like device helps reduce the debilitating symptoms of my Parkinson's Disease and helps me feel and function better than I have in several years. Even though the process is fairly routine now to the surgical and neurological teams that are trained to implant them. they will never feel routine for the patient who seeks a

DBS implant or to her or his family. The surgery itself was, as I said, routine. A large team of surgeons, neurologists, the anesthesiologist, several nurse and technicians surrounded me, each one with a job to do and a wealth of knowledge, skill, and kindness with which to do it. The part of the process where we learned more about our twenty-five year marriage was before that and after.

I usually feel uncomfortable with the term caregiver when it is referring to a spouse. To me, it is like using the word volunteer when referring to people helping out at their own church or babysitting to discuss caring for one's own child. This should be a naturally occurring part of the relationship.

My husband is a kind and thoughtful man. He loves me and I love him and he is rock steady. But I will tell you that my husband has never been so gentle, so caring, and so heroic as he has been for me this year. Every time I have needed help, he has been there. He has always needed his sleep but in dark night of doubt before the surgery, at 4 a.m. when I need help to get out of bed, when he is asleep but Parkinson's makes me feel like I am coming unglued emotionally as my right side becomes glued together, he has waked up and helped me lovingly, without complaint.

This summer he is walking with me so I can recover more completely. When my feet freeze[17]*, he helps me go again.*

I don't know how I lived with him so long before I realized he is my very own superhero. I don't usually think I need someone to save me. But I know that when I do, I can call on my husband, Frank. Thank you, my dear, for the safe harbor and the care.

We start again in two weeks to do the DBS on the other side. This time, it still won't be routine but we know what to expect.

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[17] A common symptom of PD is “freezing of gait” where the patient cannot initiate a step forward, even if they are balanced and strong. The neurological misfiring can be overcome by various cues, such as stripes painted across the floor giving the PD patient a visual target to step over, or rhythmic sounds that provide an auditory cadence that triggers a step. Eventually we would buy Adele an expensive walker that had a laser line that projected on the floor and an audible clicker. Unfortunately, like many devices and medicines, nobody can predict or explain which ones will help an individual patient and which ones won’t. It is trial and error. And unless a physician orders it, insurance won’t pay for it. In Adele’s case we spent $600 on a walker that she couldn’t use effectively.

June 2013

Adele had her second DBS surgery. If they are going to shave your head, you might as well have fun with your hair before they take it!

So, 2012 was the year we began routine visits to Ochsner hospital in New Orleans for DBS programming adjustments and ongoing Parkinson's care. For almost 10 years, every 6-12 weeks, we drove down to see the Neurology team. At first, we stayed overnight with Adele's parents in Baton Rouge or her sister Amy in the New Orleans area. But as it became more and more difficult for Adele to negotiate her activities of daily living, we eventually found it easier to make the trips as a day run and not have to worry with packing for overnight stays and the logistics of beds that were too high or too soft, showers that were too hard to get in and out of, and hauling all her medical supplies and equipment.

Those day trips were long for Adele and utterly exhausting for me. She could sleep in the car and eat a leisurely meal while I drove. I had to get her up, showered and dressed, fed, and in the car by about 8:30 A.M. Sometimes, unexpected bathroom issues would delay us more than an hour. Then we would stop near the Mississippi-Louisiana state line for scheduled bathroom visits.

Public restrooms may comply with the Americans with Disabilities Act, but that does not mean they are well thought out. Bathrooms and stalls are really designed for the most independent wheelchair users. But if you can't transfer yourself, if your helper is the opposite gender, if your wheelchair can't make a 90-degreen turn in the stall, if the toilet seat is not securely bolted on… I could go on and on about how challenging bathrooms can be. At the Mississippi Welcome Center, the plan for an opposite-gender helper is that the Welcome Center employee pulls down a partition like a garage door, dividing the bathroom into a public section and a temporarily private space. Of course, this service is only available when the Welcome Center is open, so after 5:00 PM there is no public bathroom for disabled people who need help from a spouse. Even during working hours, the employees don't monitor the doors well, so on more than one occasion while Adele and I were in the accessible stall, a woman entered our "private" space and used the adjacent stall, unaware that I was on the other side of the partition. I would stand in silence and try not to breathe, and I dared not make eye contact with Adele for fear we would laugh at the absurdity of the scene. I always wondered who the North Carolina Bathroom Police would have arrested in that scenario. How close did I come to being a registered sex offender?

July 2013

You did what? And you did it again?

In June I was finally able to go back to the Ochsner Clinic to have the second of my two DBS surgeries. In many ways, going back a second time is a lesson in working with your Strengths to achieve the most favorable outcome possible. In many other ways, a new surgery is another unknown.

Last time, in January, the night before the surgery, I was anxious and uncomfortable because I was off my medicines. We tried talking and singing.

Finally we found that reading and saying Psalm 23 helped me to focus and calm down.

During the surgery itself, I paid attention to everyone around me. This was fine, except when the surgical team began to have a bit of trouble, I heard their anxiety and magnified it within myself.

Over the last few months, I have been learning quite a bit about the way I and other people spiral into a panic, and how not to do that. During this surgery I wanted to be less mindful of the procedure and more at peace within myself.

Here are some things my friends sent me that I decided focus on:

Tom wrote:

> “Concentrate on the exhale. Slow, steady, deep and then inhale slow and full. Fill your lungs. With air. Life. Peace. Hope. Love. Get some rest. Some needed sleep. As you lie there, breathe, relax, see happy, see peace, see loved.”

Loretta wrote:

> "We must remember that this is a process you are in. It is going to require FAITH most of all that our God is taking you to a better outcome, STRENGTH to endure the process, PATIENCE to wait for the outcome, ACCEPTANCE of the results and GRATITUDE for whatever The Lord provides."

Grayson sent a quotation from Martin Luther:

> "...not health but getting well, not being but becoming, not rest but exercise. We are not now what we shall be, but we are on the way. The process is not yet finished, but it is actively going on. This is not the goal but it is the right road. At present, everything does not gleam and sparkle, but everything is being cleansed. "

Bernale wrote:

> "No way to create a silk purse out of this sow's ear, so I will simply add my prayers to the rest of those who love you. Imagine that God's lap is just waiting for you anytime you need it. Crawl on up, lean in, and listen to the heartbeat, surrounded by total love and understanding."

Jane wrote:

> "One of the themes the young people you know emphasized this year was the importance of taking off our masks in order to have a deeper relationship with God and one another. Thank you for daring to do this- you are a healer and teacher in the midst of your own struggles and help each of us struggle together. "but we also boast in our sufferings, knowing that suffering produces endurance, and endurance produces character, and character produces hope, and hope does not disappoint us, because God's love has been poured into our hearts through the Holy Spirit that has been given to us." Amen.

and Rhonda wrote:

> "Peace does not mean to be in a place where there is no noise, trouble or hard work. It means to be in the midst of those things and still be calm in your heart."

So, these are the things on which I planned to focus my mind this time.

My sister, Amy, and my husband, Frank, were with me in the hours leading up to the surgery. First, at Amy's house, then at the hospital. Amy was determined that I would focus my thinking. She read my list to me. She read it again. By the time of the big surgery, on Tuesday morning, Amy and Frank had read it to me maybe seven times. It helped, too.

The first day the first procedure was no problem. The anesthesiologists gave me Zofran in my IV. I didn't get sick and I didn't go too far under from the sedation. When I woke up, I had five fiducial screws in my skull and they had taken my cat *scan. That afternoon, the Medtronic representative and my neurologist and my surgeon would have a lengthy discussion about the best track to follow to place the electrode. The left side of my brain would soon be joining the right side.*

Monday night Frank and I both were able to sleep restfully. I have several friends who said it would be easier the second time meaning the surgery. I don't think that is true, but the waiting was definitely easier. At least the night passed more peacefully.

The implant Surgery was scheduled for Tuesday morning. I didn't take any PD medicines after midnight. The surgical team needs each Parkinson's patient to do this so they can be sure of the effective placement of the electrode. Everyone knows this and expects it. Usually the DBS surgery is the first surgery Dr. Smith does on Tuesdays but this Tuesday he had an emergency surgery to do first. We waited a very long time. Being off medicines made it seem even longer.

I grew more anxious. Without my medicine, my main symptoms were becoming more problematic and the nurse couldn't help me with medicine. I think I went to the bathroom at least every 15-20 minutes. When the anesthesiologist came to talk to me, I told her how concerned I was about my degree of anxiety. And oh boy, did she listen!

Before they came to take me back Dr. Lea came to see me. She would not be able to be present for my surgery. She had clinic hours scheduled and the emergency surgery had run long enough that she could not do both. I asked my perennial question. If the DBS on the left side affected my voice, what would we do? She told me that that was something we could not know until programming. If it turned out to be bad, we would just shut it off. She told me that the Medtronic rep, Jerry, and the blue-eyed doctor from the first surgery, an expert on brain implant electronics, would both be there and I could look for them to watch out for me. I assured her, I would be ok.

The anesthesiologist was a tiny little woman but she pushed me through the halls very quickly. When we got there to the same surgical suite as I had my *surgery in in January. It was just ordinary sized. I realized that it had seemed so spacious in January because of the bright light the surgeons had used to make their way, surgically, to my inner brain.*

Everyone was completely friendly. They welcomed me. They transferred me to the operating table. Apparently they did it onto the operating table that was turned the wrong way, foot to head. This didn't seem so major...then. They got me ready, inserted my catheter, every detail.

Dr. Smith, my surgeon, was not in the surgical suite yet. So everyone was casually waiting huddled in little clusters. Jerry stayed close, cheerily easing any anxiety I might have. Except I didn't have any because, even though I was just sedated and not anesthetized, the anesthesiologist kept my sedation pretty heavy. I was so beyond care everything seemed like a dream. I could hear everything going on, I could open my eyes with great effort, I could breathe deeply, but only when reminded. Every once in a while, the anesthesiologist would say, Miss Adele, I need you to breathe. I would remember the cues Tom has given me, "Concentrate on the exhale. Slow, steady, deep and then inhale slow and full. Fill your lungs. With air. Life. Peace. Hope. Love." It is a great thing to have such a set of cues to help you find your place physiologically in a breath or two.

Before I got to that deep place of rest, Dr. Smith had come in. He said hello and introduced a couple of people, including Hannah, a student. I mumbled hello back through my oxygen mask. And this is the one major objection I had it the whole day. I have a soft speaking voice since my first surgery. Most people can't understand me when the environment is noisy, but in a noisy surgical suite through an oxygen mask, No One can understand me.

During the initial phase of the surgery, when Dr. Smith had to break into my skull, Jerry, the Medtronic representative held my hand. Dr. Smith marked my scalp with a blue marker and a "punch" so that the mark would go through to my scalp. Dr. Smith and his resident sawed the hole in my skull. Even as sedated *as I was it is still the loudest, most thunderous noise I ever hope to hear, pretty much like a jackhammer on my skull.*

Once they were in, they spoke more intensely. The anesthesiologist lowered my level of sedation. I started to feel completely uncomfortable. My right shoulder was seized with rigidity, my legs and feet fell prey to dystonia, the muscle spasms started slowly at first then more and more quickly. T:hey had to cut the lights and everything in the room that might interfere electrically with the recording electrode. Once all sources of 60 hertz noise were extinguished, including the DBS on the right side of my brain (until that moment, I hadn't given that a thought, but it left me with instant left side Parkinson's Disease, total discomfort), Jerry had to leave me. He had a role to play with the equipment while they looked for my subthalamic nucleus. A young woman who said she was used to being in the equipment side of the sterile drape took my hand. She was very kind and she was my spokesperson for the next phase. While they recorded at progressively greater depths, she looked for signs that they had found the right spot. Really though the way I felt was secondary to the way the brain sounded as the recording electrode passed through its different regions. When they heard what sounded like a wet finger squeaking on a rubber balloon, they knew they were in the subthalamic nucleus. The surgical team, nearly everyone except for Dr. Smith, the woman holding my hand, gathered around the monitors. They began to congratulate Dr. Smith. "Textbook." was the word most frequently uttered. Jerry came back and he spent quite a while testing my forearm for signs of rigidity. When they [were] *almost ready to replace the recording electrode with the stimulating electrode. Dr. Lea came in to check the placement. I told her that the rigidity was gone from my upper arm. She asked why my leg was moving so much. I told her that the arthritis pain in my knee probably explained the discomfort in my leg even though they were right in the subthalamic nucleus.*

Now, I just had to wait for them to sink the stimulating electrode. Just a short time more to be uncomfortable. Man, that is serious discomfort. And then blessed sedation. I was aware of some things, they discussed my generator's position and decided to wait until they saw a chest X-ray.

I woke up in recovery and was looking for my husband or my mother, So they could bring me my medicine. They didn't come. Every second stretched into uncomfortable need. My nurse left the room. When she came back, because I was calling for help, she scoldingly asked, "are you making all this fuss just because your husband is not here?" "Yes," I said. "He has my Parkinson's medicine and knows that I need it."

So after several more uncomfortable minutes, I was able to ask the nurse in charge of communications what number she was calling. The number she read to me had a different area code than anyone in the family had. I gave her a correct number.

Meanwhile, my family did not know what was going on. Amy and Clark heard a page for the "Adams family," and laughed and started singing. Frank left my medicine with my mother and he and my father went to eat. While he was eating, his phone rang. "Frank, this is the recovery room nurse. Are you in the facility?" "Yes. I am in the cafeteria." "Why haven't you answered our page?" "What? My mother-in-law is right there. Who are you calling?" "Adams, the Adams family." Aargh.

Mom came back with my medicine. I was severely agitated. They finally got the nurse who had helped me in pre-op, she found the right mix of drugs in my record to help me calm down. Ativan and . And Sinemet. Blessed relief.

I slept and dreamed. When I woke up from a chasing dream where I had gone in a train car or a mine cart through a scary, funny world, my sister Amy was there, so was Frank. My mother, father, and son had gone home. I talked to Amy and Frank a little while, then went back to sleep. The next morning I was released to go home. I think I slept the majority of the time for the next 5-7 days. Everything was fine. I just needed to heal for a month and then we could activate the unit.

The month of waiting had some severely trying moments, nights, and weeks. About two weeks after surgery, I had my 30th high school reunion. It was so fun but a little too much.

The night after the first reunion event was probably the closest I have ever come to severe or permanent injury from a fall. I developed Freezing of Gait. My left foot would stick to the floor and would only take a step with great preparation and difficulty. I probably cried as many times the last two weeks before my DBS was activated, as anytime the previous six months.

Adele Hensley added a new photo to **Moving To Fight Parkinson's** timeline — with **Frank Hensley**.

February 23, 2013 · Clinton, MS ·

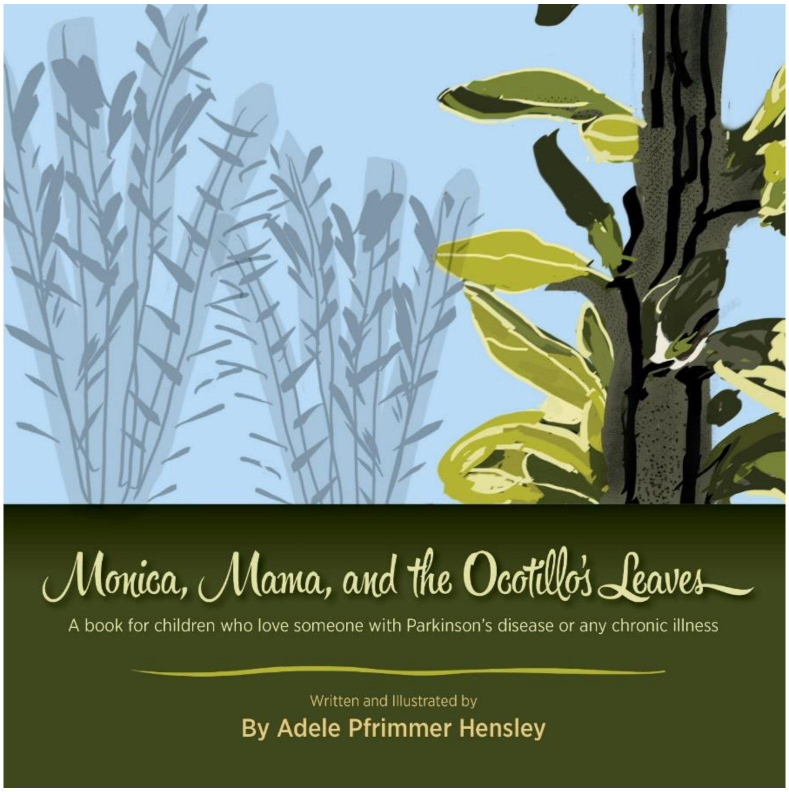
Out on my bike feeling free. Photo for you by Frank.

IX. Books Do Furnish a Life

July 2013

> *It is a beautiful morning in Mississippi. A great day to get out only I will be in for one more day to let the Synvisc injection really take hold in my knee. But at least I had breakfast in the kitchen this morning, not in my bedroom. This will be a week for expanding my boundaries, for pushing the walls back. They have been closing in way too much. Now I get to find my new intersection of COURAGE and OPPORTUNITY.*

Remember back in 2005, that draft of a story, Monica's Mama and the Ocotillo Plant? Well, look what it became in 2013:



In 2013, when *Monica, Mama, and the Ocotillo's Leaves* was new, Adele left a copy with her podiatrist. Ten years later, in 2023, I consulted the same podiatrist about my own foot pain. One day, as I was leaving the clinic, the staff had straightened up the waiting area, and there, perched on the fireplace hearth, was Adele's book…

August 2013

I am waiting for my friend to come over so we can play together on the Wii. That is right, we two women "of a certain age" are getting together to play on the Nintendo. My friend has had her DBS implants much longer than I have had mine. She has trouble with her balance still, after all these years, so she uses her Wii fit to help improve her balance.

I have had a Wii-fit for years. In Chicago, I used to use it a lot. I do not even think I have played once in the two years since I moved to Mississippi.

Now I am beginning to wonder what other tools for healthy living I already own and simply have not been using.

Last Thursday morning was pretty good, I felt good, like everything was going my way.

By evening it turned out to be one of "those" days. I thought, "What?!" I felt like the lowest form of hypocrite for having written such a sunny blog post and then for feeling so emotionally bad only three hours later.

One of my friends from Chicago asked me was I keeping a daily schedule or was I winging it? She suggested that I schedule myself a bit more conservatively than I have been living. She suggested that rest breaks are a good thing, and I should take some.

It has been a week, since my life turned into an emotional mine-field. Here is what I have learned this time around:

The higher my DBS voltage, the more emotionally strong I feel.

When my levodopa levels are High enough, I feel emotionally stabile.

Riding my bike, a recumbent trike, can really give me an emotional boost. After 20-30 minutes of pedaling I feel completely at ease. It is like an [instant] *response to the endorphin rush.*

Riding my bike can really take a toll, too, if I let it make me too fatigued.

I am feeling MUCH better now but each day seems like I am playing it out on a cosmic Wii fit. If I can find the balance point between enough medicine, enough voltage, enough rest, and enough exercise, I can have an emotionally stable, easy day. But if I get out of balance, I might as well know that all I am going to be able to do is cry or sleep. I may have a computer implanted in my brain, but the path I am still only human and the path on can only be travelled with baby steps.

Frank Hensley
September 8, 2013 ·

I'm so proud of my wife's hard work. She biked more than 7 miles this afternoon. Not bad for a girl who can't walk!

September 15, 2013

Dance for PD has come to Mississippi
Of all the possible forms of movement that have been developed for people living with Parkinson's, the two that I most wished were available in Mississippi were a boxing gym and dance for PD. One wish has been granted. Damce for PD is being offered at Millsaps College every Monday night this fall.

You might ask how I could be excited? I'm still not walking independently, how could I dance?

At Dance for PD, you soon realize that even if you are seated, you can be dancing.

Yesterday a Dance for PD workshop was offered. It was taught by two of the founding teachers of the program: Misty Owens and David Leventhal. It was a challenge to each person mind and body.it was also one of the kindest experiences I have had. When the class stood to dance with a chair for support, I tried it. When I realized it was too much standing amd I should sit, one of the class leaders sat, too. And showed me how to execute each step in a chair. Any time it seemed like sitting out was the only possibility, a teacher was right there to show us how to dance while seated.

I won't always have to dance from my chair but I will always remember thus particular way the teachers were kind.

The class willl be Mondays at 6 pm in the MAC at Millsaps. It is free to people with Parkinson's.

*****

In 2013 I joined a small private online support group of spouses of people with Young Onset Parkinson's Disease (YOPD). In the group, we spouses turn off our filters and say the things we can't say in front of our Person with Parkinson's (PWP) or other family members. It's a place of raw emotion, anger, helplessness, bodily fluids and dirty dishes. But it is also a community of support, strategy, commiseration, and occasionally celebration. One of the founders of the group will always be known to me as the one who told us she cries in the shower, where her PWP can't hear or see it. I won't share anything more about the group, out of respect for other members' privacy, but I do want to share some of my posts to the group because they captured what I was thinking back then…

Frank Hensley to [group]

(Some context: in 2013 Michael J. Fox, who is the most famous PWP, was starring in a TV show about a character with Parkinson's.)

September 2013

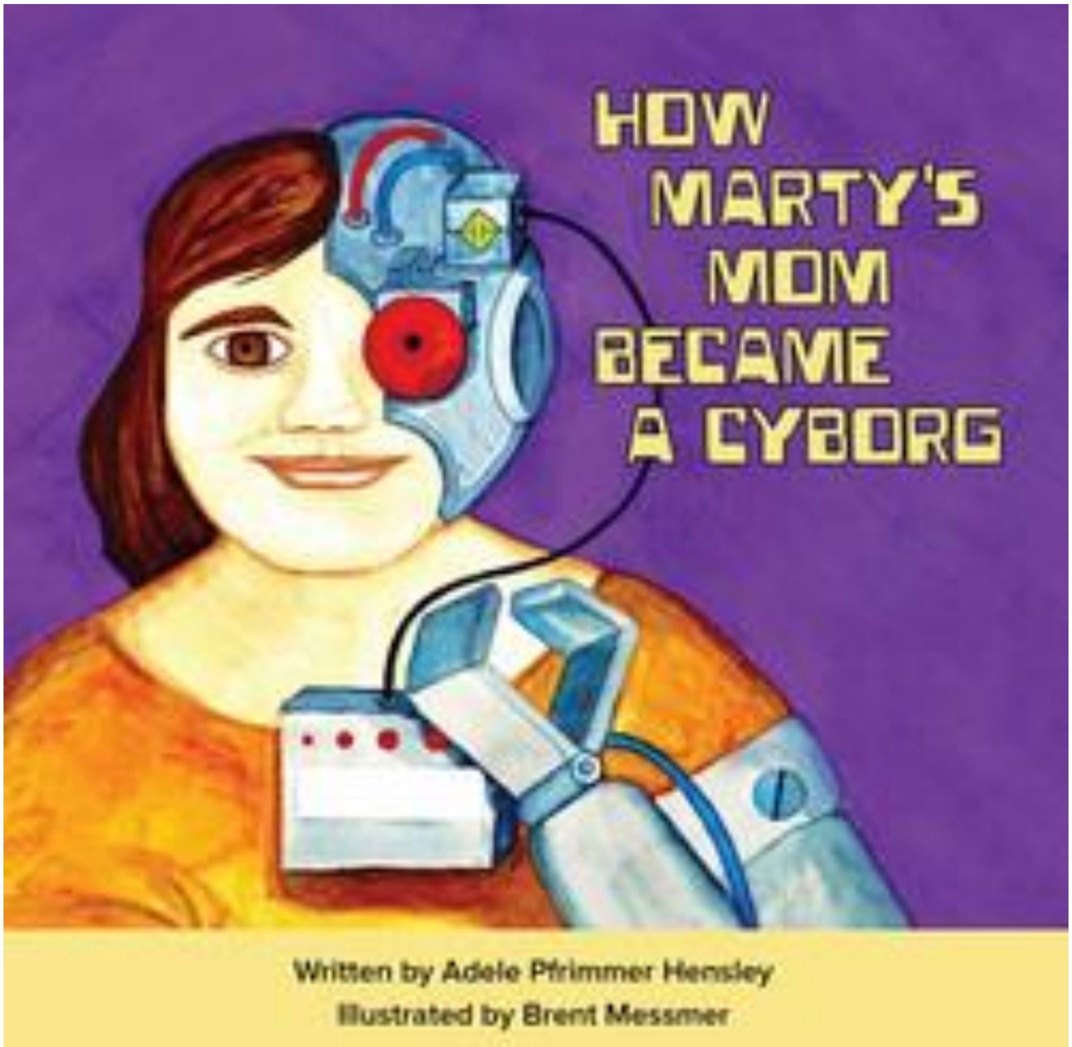
Real life PD humor: I normally take her breakfast in our room, since she takes a while to get mobile. I was eating mine at the computer when she sent me a Facebook message that she had accidentally flung her spoon over the headboard, and it was under our bed. Had to take her a clean spoon and then crawl through the dog hair to retrieve the wayward one. I don't think you'll see MJF's TV wife crawling on her belly to get a spoon from under a bed. And I should probably vacuum up dog hair before my mother visits next week.

Frank Hensley to [group]

October 2013

I've got something to put away in the back of the house, but I know if I go back there, she'll ask me for a series of favors that will take 15-20 minutes. So, I'm avoiding her, just to try to get bills paid and paperwork done before I have to go teach. And I feel really guilty about it.

In late 2013 Adele published her second book for children about Parkinson's Disease. This time she told the story of DBS surgery. Of her books for kids, it is my favorite. And our friend and taekwondo instructor Brent Messmer drew the most delightful illustrations for it.



October 2013

DBS surgery damaged Adele's balance, but it restored some mobility, and by the end of the year she was regularly riding her recumbent trike around our neighborhood.

> *I guess I was not in a fit state to take a photo. Trike left wheel flipped up. I overcorrected and skidded hard on the right. The trike left me on the road and finished flipping over a bike length ahead of me.*

[No falling, dammit!]

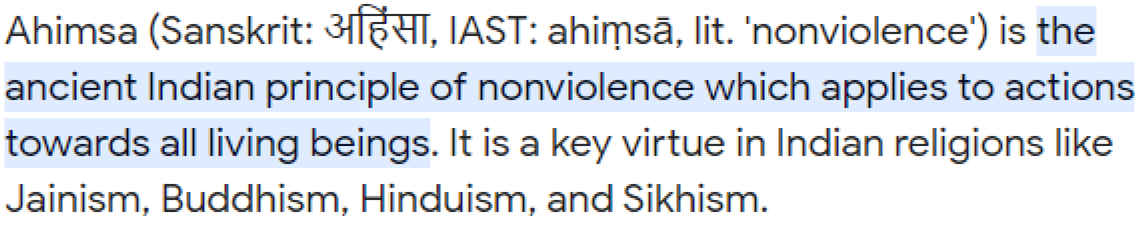
> *Today at physical therapy left kicks were hard so hard. I told my therapist that I thought they seemed so hard because they were something I used to be able to do. He looked at me quite seriously and said you just can't make comparisons to what you used to be able to do. Everything is different. Right then, I was flooded with the certainty that I*
> *Know This. Comparisons are painful or harmful. Expectations set a person up for disappointment. Instead of accepting the physical abilities my body brings with it each day and being satisfied and grateful, I have greeted each*

day with a comparison to the past and an expectation of improvement.
Ahimsa.[18]
Detachment.
Kindness to self.
I think I start over tomorrow...

Frank Hensley to [group]
October 2013
Saturday evening, Adele went for a ride on her trike. She was only 7 miles short of 400 since her second DBS, and it was her 100th ride for the year. So, she was really determined to get 7 miles and claim 400 miles. But instead, she did things at Parkie speed and had to quit after only about 5 miles. The gatekeeper locked the park, so my Parkie had to park and wait for the cops. The Jackson Police don't have keys to the gate to a Jackson city park, so it looked like she was going to have to leave her car and trike overnight. I went to rescue her, but it turned out that one of the gate keepers showed up with a key. So, after drama and flashing blue lights, she got home safe and sound. And today she rode 5 miles, pushing her over 400. I'm very proud of her!

---

[18] Adele! Woman with the giant vocabulary! Here I am trying to let you tell your story, and you go and make me look up words you posted on Facebook 10 years ago.



Ahimsa (Sanskrit: अहिंसा, IAST: ahiṃsā, lit. 'nonviolence') is the ancient Indian principle of nonviolence which applies to actions towards all living beings. It is a key virtue in Indian religions like Jainism, Buddhism, Hinduism, and Sikhism.

Frank Hensley is with **Adele Hensley**.
October 24, 2013 ·

Adele's blue box that helps her travel through space and time. Given how much medication I cram in there, it must be bigger on the inside than it is from outside. I married a Time Lord.

December 2013

Anyone who has ever heard me sing will recognize the absurdity of this image below! I joked with Adele that this was the first sign that she was losing her cognitive ability as her Parkinson's progressed! I'm not sure what website she used to create the image, but she captured how I feel when a favorite song comes on the radio, and how she responds to my terrible singing.

Adele Hensley added a new photo.
December 14, 2013 ·

Adele thinks Frank rocks!

2014

Frank Hensley to [group]

February 2014

Forgive me, caregivers, for I have sinned. I lied to my wife this morning. I made her a medical appointment for 10:30 but I told her it was at 10:00. We arrived at 10:25. She does not know we were on time. How bad should I feel? Do I confess?

March 2014

With Gryffindor the Labrador

April 2014

> *Warning. This is my long answer to the question "how are you doing?" If you want to skip it, please feel free.*
>
> *Let me start here: I feel a lot better. I do not feel a sense of anxious desperation like I did for the last few months. I just feel like myself except for the short periods of time when my medicine wears off.*
>
> *Many thanks to my friend Maria De Leon, MD. We talked on the phone, never easy for the people trying to understand what I say, and she asked how I was recovering from the adjustments to my DBS. It really helped me to think about this as a process of recovering instead of as a case of the*

programming not being effective. Thanks too to Michelle David Lane who reminded me that this is baby steps and that through a series of adjustments it can get even better. Thanks to Sandy O'Quinn West, who reminded me to treat myself gently when I begin to feel impatient and to Patricia Robinson who has had her own difficult year and so understands the desire to be finished with the process but who still knows it is a process.

When I saw the doctor last week for programming, he was able to adjust out several side-effects of my stimulation. Because of this he was able to turn up the voltage to each of my stimulators. When he turned the electricity off, I did see that my right side has gotten much worse. It used to be that the right hand only showed a trace of Parkinson's disease. Now it is completely rigid until my medicine levels rise to their optima. When my medicine is good, my emotions are fine, my right hand works as agilely as I could wish. As long as I maintain an upright posture, I can breathe freely. I can stand better and more easily than I could before my adjustment. I can actually speak more clearly and sometimes sing when my medicine is zipping along into my brain. I can walk better with my walker than I've been able to in months. I cannot walk off the walker. Maybe this will get better. I don't know. Maria reminded me that while I am recovering, I'm going to need more dopamine, but that will settle out. It doesn't mean that my dosage levels will always be high. I think this doctor is an excellent programmer. I don't thing I will have to go to another clinic (but I'm not ruling it out). When he finished last Tuesday he did warn me that my gait and balance might not get any better but know those are much more likely to be restored through therapy than programming. He also said that there may not be a lot more he can do. Well there might not, but there might. Thank you to Bob Pfrimmer for driving me down and remembering that the doctor said to "go home and let it percolate." And to Amy Pfrimmer for being there, making me laugh, and listening closely to what the doctor said so when I needed more dopamine, she could confirm Dr. H.'s advice.

April 11, 2014

World Parkinson's Day 2014

These are the central challenges of my existence with Parkinson's: how to engage in the daily struggles for every bit of normal life possible, always hoping for a cure to be found and used, while trying to minimize personal stress, anxiety, and the specter of humiliation that taunts me at every turn. There are days that I would swear this illness has a will and an agenda. That it has a plan to dismantle my life completely, from standards of personal hygiene to my closest relationships. I know it is not a character driven by intent. I know this is a disease with no known cause; that it sunk roots into my brain maybe ten or twenty years before it was discovered or suspected. Being hit with a case of Parkinson's disease may be as random as being hit with a meteor, I've never calculated the odds, but even though the meteor would hit faster the destruction caused by Parkinson's will likely prove to be no less devastating, unless...

Unless THIS is the right time for the right researchers, either the students of mis-folded proteins, or growth factors, or autologous stem cells, or some group of brilliant, well-prepared, hard-working, driven, because they all are or they would do something more certain and more profitable, scientists, to find AND spread a cure for this disease.

No, Parkinson's disease does not kill. It dismantles almost every single one of a person's abilities until independence becomes a distant memory. I have hope that a cure is near. I will keep exercising hard (the only treatment known to drive back the progression of Parkinson's) and eating right (the thing that we each can control that may come close to a cure) to be ready for a cure.

In 2004, when I was first diagnosed with Parkinson's disease, there was really no prognosis for anyone to live longer than about ten years with it because most people who develop Parkinson's are in their seventies, or eighties and that was as long as they were expected to live. I was 38. Now, thanks to Facebook, which also had not existed very long when I was diagnosed, I know a LOT of people *with Young onset Parkinson's disease. I expect to live ten more years and then ten more and another ten. I expect most of my friends with Parkinson's to live long lives, too.*

Many of us have had Deep Brain Stimulation surgery to enhance our quality of life. We are doing our best to LIVE in the face of Parkinson's disease. Most of us take an array of medications every day. No matter how dramatic the drugs or the treatment, nothing that we have available now is "disease-modifying." This means that the existing treatments treat symptoms but they cannot address the cause or the progression of anyone's case of Parkinson's disease. So many diseases exist that are incurable and that are progressive.

I know this is just one. It is the one I have. It is the one that has taught me things about myself that I really would have rather never learned. It is the one that I can write about, that inspires most of my poetry, that I can ask people to band together against.

May 16, 2014

With Gratitude

Twenty seven years ago,
surrounded and supported by
our family and best friends
We stood together, holding hands
and made eternal promises.
When we were done
We walked together underneath a
patch of light from a window and
shared a kiss and a dance of glee.
We didn't really think of the loved ones
we'd assembled as embodying more
than goodwill and love but they have
shown us again and again that

among their blessings were
Faith,
Faithfulness,
Hearts Burnished with prayer,
Friendship,
Longstanding companionship,
Grace ,
A hundred kinds of patience,
And a thousand ways to love.
And on this anniversary,
which is neither the beginning
nor the end of our story,
we are grateful.
because we have seen such communities
Rising up wherever we have lived
Adding to and filling in for that original assemblage.
Teaching us, loving us,
Seeing us through.

We thought
We have thought.
We keep thinking
That if we could make it a little longer,
We would be ok.
But the truth is that 'we' has usually meant
more than just the two or even the three of us.
because it has meant all of us.

Frank Hensley to [group]

May 2014

Yesterday Adele's PT session involved nothing except walking 5 laps around the clinic. No walker. No cane. Her PT put a "gait belt" on her and held it for safety, but she WALKED on her own. A huge hopeful step for us!

Frank Hensley to [group]

August 2014

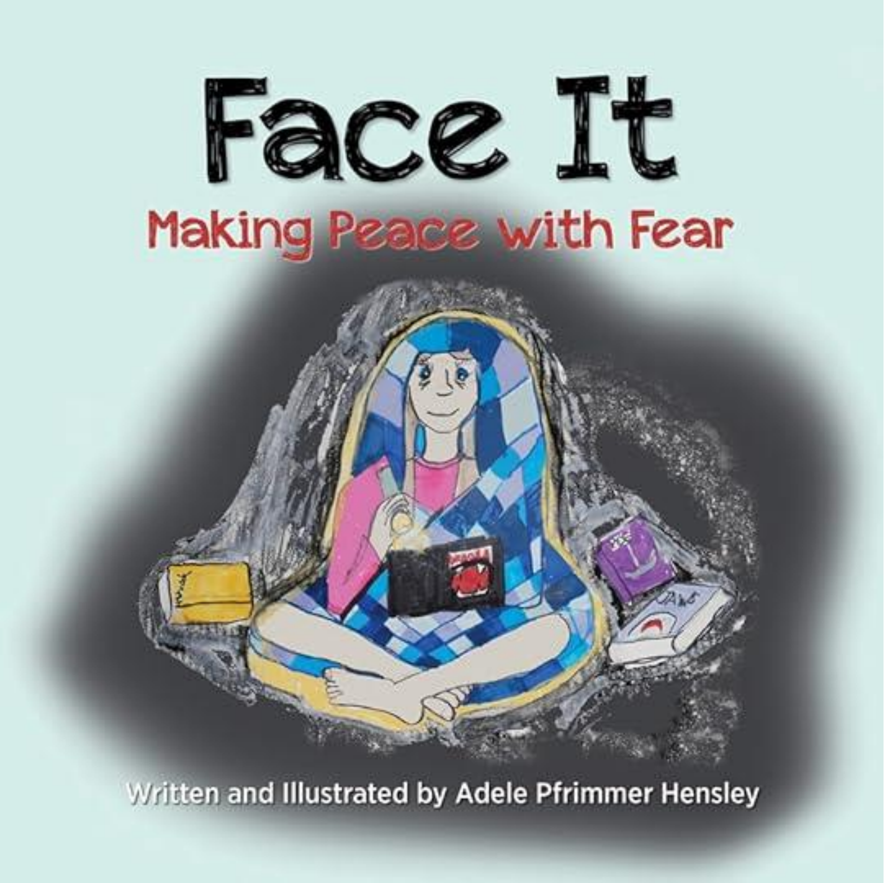
A DBS programming update: A week and a half ago, Adele had her system reprogrammed. It felt great and she walked without her walker the next morning. But 48 hours later it all fell apart, and she was a complete wreck. Any adjustment to DBS can stimulate the brain in positive ways that are temporary (a "honeymoon" effect). So, by last Saturday she couldn't walk, couldn't talk, couldn't get dressed, and cried most of the day. Worst day of PD for us in many years (ever?). I figured out that the new electrical field shape was excellent, but the lower voltage was the problem. She didn't want to just turn it up without her doc's supervision, so on Thursday we drove back to New Orleans (ugh. I'm tired of I-55!). He cranked her up about half a volt and the last 3 days have been much better (she's only cried twice for about 3 minutes each time).

Tonight she was feeling tired and off, and she cried a bit. I suggested another 0.1 volt, but she promised the doc not to try more than 0.2 per day and she's at her limit. I pointed out that if she takes more Sinemet and gets dyskinetic, she'll have to put up with the effects for quite a while, but if bumps the voltage up and gets dyskinetic, she can just turn it down and poof - dyskinesia gone. But she took the Sinemet.

One piece of advice I'd share for anyone doing DBS long distance is to beg for or demand that they give your PWP some control over the settings. If it takes a week of misery to get back to the doc for an adjustment, the doc doesn't have to cope with that, but WE do.

Frank Hensley to [group]
August 2014
19 months after her first DBS and 13 months after the second she is finally well adjusted! Two weeks ago we had one of the worst days of her 10 years with PD, but today has been one of the best. If you're considering DBS don't expect too much benefit right away, but don't give up hope because a proper program makes a world of difference.

In 2014 Adele published her third book for children, *Face It*, about facing her fears. These book projects gave her a sense of purpose, productivity, and self-validation. They never made any money. Book sales covered our publication costs, more or less, but that was never the point. Adele gave away more books than she sold.



August 2014

Someone, I no longer know whom, sent Adele some questions about her books. Here's what she wrote in response:

In 2003, I was the mother of a three year-old son. I had been a college biology teacher and a choir singer, and a storyteller, but during my son's first year, my voice stopped working properly. After I had spent several years concerned and seeking what was wrong with me, my doctor diagnosed me with Parkinson's disease. I lived in Phoenix, Arizona and enjoyed frequent walks in the desert.

In 2004 my husband and I decided to move to Chicago, Illinois. I realized that I would never be able to share the desert with my son the way I had imagined. I wrote a story for him to read when he was older that I hoped would help him understand the turbulent time leading up to my diagnosis and how much I loved the desert. That was the start of my first book, Monica, Mama, and the Ocotillo's Leaves.

In February of 2013, while I was recuperating from my first deep brain stimulation surgery, I had an online conversation with several other women who are living with Parkinson's disease. We were discussing the need to promote awareness of Parkinson's, especially to increase early diagnosis. Even now, there are only about a dozen books for children dealing with Parkinson's disease, and three of them are mine. We are coming to learn that the earlier in their disease process that people living with Parkinson's disease start participating in vigorous exercise, the more they can slow the progression of their disease. This conversation challenged me to open up my nine year-old story and see if I could illustrate it.

I asked my friends to give me two weeks to see if the illustrations would work. We all agreed that I needed more drawings but these were of an acceptable quality that it would be worthwhile for me to keep drawing.

When I finished, we were brainstorming ways to spread the story, to increase awareness. One of my friends on Facebook, the owner of a small press, was a *close friend with one of her authors, who was dying of the complications of Parkinson's disease. Because of this friendship, thewordverve inc (www.thewordverve.com), was also interested in Parkinson's disease awareness. Jan Fix became my editor and my publisher.*

This was when I came to understand the theme that would lie at the emotional center of my next several books. Parkinson's disease has many frightening aspects for the adults who are living with it. They are frightening for their children, too. With Parkinson's, these are often physical qualities, such as hunched shoulders, clenched fists, and drooling. For Parkinson's and other chronic illnesses, frightening symptoms may be movement related, or they may be non-motor, including psychological, symptoms. When children are able to speak freely with the adults they love, they can understand what they are feeling and why. They can learn ways to help themselves cope with their fears or their anger and they can learn ways to help the adults in their lives, too.

My books have been received with gratitude by people who are looking for a way to open a conversation about chronic illness with a child that they love. They would be a useful addition to a counselor's office, a neurologist's office, a church library, a school, anywhere that children may be found who can benefit from an opportunity to enhance their emotional resilience.

I will mark ten years of living with Parkinson's disease on December 28th this year. While Parkinson's does not control me, it makes everything take more and does affect nearly every part of my life. I had deep brain stimulation surgery done twice last year. In some ways, it was very successful. In others, it was not. So, I can sleep through the night and I am rarely troubled by rigidity, but my mobility is impaired and I can walk only with a walker.

One physical task that gives me trouble is performing fine motor skills with my hands. I was able to draw the pictures for my third book, <u>Face It: Making Peace with Fear</u>, by drawing very large pictures. When I could not draw clearly in a notebook, I bought rolls of paper ten feet long. Most of the final drawings are about 3 feet high by 4 feet long.

August 2014

How do you know when you've reached über geek status about your own books? When the Tylertown Friends of the Library invites you to speak and you are (I am) so excited that you never realize how much more sense it would make to speak during April, Parkinson's Awareness Month, until you've already accepted for March. Thank you to Mr. John Thornhill (Amy's dad, Martha's husband)for managing to get me invited. I'm really looking forward to it!

September 2014

My friend Gary Schmitz nominated me for the thankful challenge. Each day for a week, I get to post one thing I am most thankful for. I am supposed to nominate three people each day but I'm going to celebrate the beginning of fall tonight by skipping that step. I think this week will end the summer of challenges so as to make room for something new.
I am thankful for my husband, Frank , and my son, Clark. I feel like I can't remember being 100% well since the beginning of my first surgery on January 7, 2013.
These two have helped me, loved me, stood by me, comforted me, laughed with me, and understood me at my most unintelligible. Frank says of our situation, "it is what it is." He reminds me that this is Parkinson's disease. It is not anyone's fault. If I ever waver in my confidence or sense of security, all I need do is remember Frank's friendship, his care, and his tenderness during 2013 and 2014. This is what love looks like.

Frank Hensley to [group]
September 2014
Speaking of loss of executive function and being bad with $, I just found out that she has donated almost $400 to an orphanage in Uganda this month, without telling me. And now she's not so sure the orphanage is legitimate. I think she has been scammed... and we sure don't have $400 extra! We already support our

church, a local orphanage, a ministry against human trafficking that my cousin works for, and a sponsored child in South America!

October 2014

Adele's friend LeDayne worked for the Baptist Peace Fellowship. She asked Adele to contribute to a collection of brief reflections by people who viewed their work as peacemaking in one form or another:

A NEW CALLING: MY VOCATION AS A PEACEMAKER
Vocation of Peacemaking (vol. 1) Published October 20, 2014

I stopped professional work in 2011 when my Parkinson's disease made working full time too difficult. I had not looked at what I do now as a vocation to peacemaking until I received LeDayne's invitation. Since the autumn of 2011, I have been writing poems about having Parkinson's disease. At first I thought they were to help me deepen my understanding of my relationship with the disease. But now that three years have passed and I have written three books to help children who love adults with chronic illnesses, it seems more focused and more of a ministry with two foci. I write my children's books to help empower children. Children who are confronted with the illness of an adult who "never gets better and always gets worse" are children in a frightening situation. My stories show them that they already know ways for helping themselves cope and for comforting the adults they love. I write my poetry to educate and communicate that despite there being times when Parkinson's has control of my voice and facial expressions, I am still inside this somewhat unwieldy body. I try to translate the experience behind the stiffened facial muscles to let people with and without Parkinson's know that, although it is hard sometimes, this is very much a life worth living.
Included are two examples of my current work. The first one is about being available online to help people who have recently had their Parkinson's disease diagnosed. During a recent program on PBS called Robin Williams Remembered--A Pioneers of Television Special, I tweeted @parkinsonhope2, in

hopes no one would have to feel alone. The second poem is about patience, the flip side of hope.

A NEW CALLING

This summer there was a man who died.
So kind and famous that everyone cried.
Then the news traveled over the air,
the man had perished because of despair.
The whole country was saddened when this was made known.
We had felt like we'd known him. Yet he died all alone.
Later we heard some more shocking news
from the famous man's wife and it made me quite blue.
He had Parkinson's, she shared.
Maybe he felt that nobody cared.
Each case is different. It doesn't cause death,
but Parkinson's makes you feel like a terrible mess
The adjustment to the disease and its drugs takes some time.
They take hope-filled support and enough strength to climb
out of a self-pitying state of your mind.
We can't help the man; he is already gone.
But we can share hope with others and a way to move on.
Upon diagnosis, you may feel quite alone.
If I can help it, you won't be on your own.

PATIENCE MAY BE MORE LIKE A COCHINEAL INSECT[19]...

Patience has no feathers.
Oh, it may look that way,
but the more closely you look,
you realize that what looks like feathers
are really tiny fakes of wax.
Patience has no real ability to move.
It sits on a leaf
and shelters in place.
surviving,
still.
It doesn't seem possible that it could thrive but if you don't
try to force anything,
if you leave its protective covering in place,
if you can just let it be,
when you return,
it may have multiplied a thousand-fold,
it may cover the plant that grew from the seed of hurry or
worry in your heart.
draining its power,
halting its progress,
stopping it cold.
And when the trouble is done, and all the patience you need
for what lies ahead
is once again a small source
and deep knowledge
of the process of the cultivation of patience,
the excess can mark your soul the deep rich red that will
speak forever of your perseverance and the
indomitable spirit that is you.

---

[19] Cochineal insects suck the sap from cactus plants. They sit still and cover their bodies in a waxy coating that hides them from predators. They are a source of a natural red food dye that you may find in the ingredient list of various products such as red candy and red beverages.

November 2014

A cinquain with a thought about
why I'm not freaking out
(except via poetry)
when I'm having my
knee replaced tomorrow.

It's not
the same getting
ready for surgery
that you know you will sleep throughout.
No sweat!

Adele Pfrimmer Hensley
19 November 2014

Last time they drilled into your cranium
this time a knee of titanium
do not dread
you'll spend time in bed
and come home with hair on your brainium

Frank Hensley
19 November 2014

We had hospital cafeteria food for Thanksgiving dinner. The rehabilitation facility suspected that Adele had developed a blood clot; the ultrasound technician that was called in had spent the entire morning cooking for her family, but then left them at the dinner table to come check Adele's veins. Adele was fine; no clot. Adele apologized profusely to the tech, and tried to convey her gratitude, but she still felt guilty about "ruining that nice lady's family dinner."

Frank Hensley to [group]

December 2014

I thought that while Adele stayed in the rehab hospital I would enjoy a nice break from caring for her. Instead, I'm missing her, worrying how her therapy is going, and feeling guilty for not being there... I won't see her at all today because as soon as work is over, I have to feed the teen and get us to karate. I plan to be with her tomorrow morning, but not seeing her today is not easy. Plus, today she should hear from a case manager a projection for how long she'll be in rehab, and she'll have to face that without me there... This care stuff isn't easy, is it?

Frank Hensley to [group]

December 2014

Adele will come home from the hospital Friday, 15 days after surgery. We are getting a new potty chair, a new bath bench, and planning to rent a wheelchair for a few weeks. She has new tools like a dressing stick that helps her pull her own shoes on, a tool to help with socks, etc. I'm looking forward to not driving to the hospital every day and to having her HOME.

Home Tomorrow

I’m going home tomorrow.
I’m going home from the hospital tomorrow.
I know my therapists at the rehabilitation hospital
would wrap me in bubble wrap or
keep me two more weeks
if we all had an infinite supply
of money, or time, or personal energy,
you know, the currencies of our world.
Instead they send me home
well-equipped to face all manner of unexpected foes.
The halting step, instantaneous fatigue, a sudden fall.
For protection I bring home a wheelchair a new walker a shower bench and a seat for my toilet.
Saturday the first home health worker will be at my house.
We will trace safe paths through my home.
But the real protection will come from being surrounded by my family once again.
Even when my son and my husband go to school, my dog will be with me and I’ll no longer
be
alone.

Adele Pfrimmer Hensley
4 December 2014

X. Sleepless Grubby Boy

Frank Hensley to [group]

December 2014

I'll bet some of you can relate... I went to bed about 11 after helping her get to the bathroom. But for the next hour she kept making random noises, so I didn't get to sleep. She finally came to bed at midnight and we both went to sleep. Then at 1:50 I heard her crying "Help! Help!" and found her back in the bathroom with her feet stuck to the floor. No, she hadn't taken Sinemet when she got back up. So, until 2:30 I was helping her - first to sit on the shower chair, then to transfer to the toilet, and finally to get back in bed. So, I slept for real from 3:00 to 6:00. I've got 2 final exams to write today. I wonder if they will include any complete, grammatically correct sentences. And God have mercy on the authors of the term papers I hope to read today.

2015

Frank Hensley to [group]

February 2015

Too much voltage + too much Sinemet and she throws her bowl across the room... New Special Olympics event: the Dyskinesia Discus.

February 2015

a sonnet for wrens, Valentine's, and spring

The wren's song rings proudly between greedy
mouths full of suet in the clear morning light.
Camouflaged, white and brown. He is small, lurking, speedy.
He hides but his song fills the yard with delight.
Though I am delighted; the wren's working hard,
Attracting the lady wrens just to find one
to be his dear mate. Share a nest in the yard.
He sings it loudly. He longs to be done.
He doesn't know it but that's the why he sings.
He wants to have sex so he risks his life.
"Consequences?" He might ask. If he knew of such things.
He doesn't know he's really courting a wife.
It starts out with romance summed up in a song
The song ends in devotion that lasts his life long.

Adele Pfrimmer Hensley
9 February 2015

Frank Hensley to [group]
March 2015
We watched the movie "The Theory of Everything" about Stephen Hawking. It focuses on his relationship with his first wife, Jane. The portrayal of caregiving was by no means complete, but I felt they did a pretty good job of showing some aspects of her commitment, her frustration, and her desire to give their kids a normal life. I don't think anyone watching with me found it hard to watch, but I struggled a bit not to leave the room in a couple of places. I recommend the movie, but not without caution that some caregivers might find it too much. Jane and Stephen divorced after about 15 years of marriage and watching their relationship change was really the worst thing for me.

Frank Hensley to [group]

March 2015

2 hours to shower and dress. 3 hour drive to the hospital. 1.5 hour appt with MDS[20]. 1 hour dinner in the hospital cafeteria. 1 hour in the hospital bathroom. I'm exhausted and still have a 3-hour drive home once she's finally ready to go. But at least I know some of you can relate to this!

Frank Hensley to [group]

March 2015

Dreaming. Screaming. Clawing at the husband. Thanks, Requip.

Frank Hensley to [group]

March 2015

After having her DBS voltage cut in half two weeks ago, Adele has been gobbling lots more Sinemet. Her emotional meltdowns got much better except when her feet stick to the floor. She went from 8mg Requip to 10 mg and that has helped significantly. Today she jumped up to 12 mg... Rode her NuStep exerciser hard this morning, attended 8th grade awards night, went to the meeting for marching band parents, came home and took a shower all by herself. She never touched the wheelchair, her feet never stuck even when walking backwards into our cramped little shower, and she NEVER CRIED ALL DAY! Requip is my favorite!

---

[20] Movement Disorder Specialist

March 11, 2015

Lunchtime in Tylertown

Yesterday I went to the Walthall County Library in Tylertown, MS. I spoke for about 30 minutes on my life has an author and person with Parkinson's disease. I read some from Face It. Three very good parts of this day included: my voice kept on working and my vocal folds did not spasm, a very kind man from the audience came up to me. He said he had been a speech teacher. If a speaker is anxious about their voice, nearly always relaxes after a few minutes and the listeners (who I must remember are nearly always rooting for the speaker) understand their manner of speaking better and better as the talk goes on. The third very good part was I got to know Mr. Thornhill better during the car ride there and back. Besides keeping a tree farm in Walthall County; Mr. Thornhill works all the time. He drove to Clinton, took me to Tylertown, brought me back home to Clinton, and without coming in, headed back down the road to Tylertown. If that is not enough, this is a gentleman who decided to Hike the Appalachian Trail, by sections when he was 66 years old, more than ten years ago! Let me tell you, I am impressed like crazy. I think that my new person to model myself after is Mr. John Thornhill. Thank you Mr. Thornhill.

March 12, 2015

My pastor has been urging us to find a way to serve God through our church. At this moment, I stand one person's effort and good will away from being home bound. This is not where I expected or wanted to end up at the age of 49, but between realizing that I was no longer a safe driver and some other mobility problems from my Parkinson's, I have had to come to rely on my husband for transportation (I live in a town without a bus line). I also cannot rely on the strength of my voice like I used to. Last Sunday I spoke with my pastor. I asked where can I serve? I do not really belong. He answered quickly that I could best work through Facebook. That's really a continuation of what my Facebook has been. I realized that I have this blog, which I haven't written for since September. So I'm repurposing the blog today. Now it will be for personal as well as authoring purposes. I think that is the way God works - our independence *becomes interdependence and our professional becomes personal, so that when we confess our weakness, God transforms it to strength and uses us.*

March 19, 2015

A Doctor's Appointment

Tomorrow I'll be riding down to New Orleans to see my doctor for the first time since October. I feel a little at loose ends because for ten years now, since the fall of 2005, I have seen my movement disorder doctor every four months. Tomorrow, though, marks five months since I traded in my knee joint for a replacement built by DuPuy. So much has happened since my knee surgery - for me and for all people who have Parkinson's disease. The FDA has approved new formulations of levodopa and amantadine, and results from a small study of DBS settings have been released. I'm pretty sure that my worst dyskinesia and my worst speech is associated with anxiety. It's all too much for one twenty minute appointment but I've written my doctor about my priorities, concerns and questions. I hope it helps me stay on track.

March 27, 2015

Ch-ch-ch-changes

A lot happens in a week!
One week ago I went to my doctor. He raised the voltage on my deep brain stimulators by half a volt on each side. By doing so, once I had slept under the new conditions, my doctor and I seemed to unlock new layers of ability without dyskinesia.
When I got to physical therapy this Thursday I showed my therapist pages 110-115 of John Pepper's book, the section on conscious walking. He read them and he started thinking. It didn't take long before I was praticing walking WITHOUT a walker for the first time since my knee replacement surgery November 20!
It was hard, it was scary, it was not very good, it was WALKING!
Thank you to Dr. Houghton for the ability , to John Pepper for the possibility, and to Matt Thomas for the creativiity.

Just imagine the parade. Me followed by two men holding tight to my gait belt; they are followed by a Third person pushing a chair.

April 3, 2015

Neuroplasticity...this is not your father's Oldmobile...

These people [picture redacted] *each have young onset Parkinson's disease, Parkinson's that makes itself known before the PWP (Person with Parkinson's) is 50. April is Parkinson's Awareness Month.*
Do you remember the Oldsmobile commercials from the eighties? That's how I am starting to feel about my brain.
I have been practicing walking without a walker in physical therapy. The last time I tried it was before my knee was replaced in November 2014. I favored one knee very strongly and I tried to walk like I always had. I wasn't too successful. This time it is different. Nothing hurts, so the only times I limp are when I do so out of habit. We are trying to use neuroplasticity, the ability to build new nerve trackways to do old tasks. When I think "knee up" with every step, I am walking a new way. Almost "on a new part of my brain." I'm not limping. I told my husband that this kind of walking was so strange that it felt "fake." He said that he is not surprised. I'm not walking automatically, like I have for 48 years. It feels fake now until the new skills become habits. Well. I didn't expect this but it makes sense to me.

undated, 2015

The year I taught myself to walk again

I started to teach myself how to walk again in January, just after ten years had passed since I had been diagnosed with Parkinson's disease and just before my forty ninth birthday. The first time you learn to walk, when you are a baby, walking is cute. You pull up on whatever is handy, the couch, a chair, the coffee table. People hold out their hands to catch you. They smile and call to you! You wear a thick piece of padding, a diaper, that cushions the blow when you fall.

When you are an adult, who has walked your whole life, your relationship with walking is not an unmixed pleasure. Part of you can't believe you have to do this again. You are afraid that you will fall. You know the consequences of a fall could damage you. After all, you aren't wearing a diaper for padding. If you were, you are not sure where you'd put it. Nobody smiles a welcoming smile or holds their arms out to you, either. They seem to figure that something is wrong with you or you would know how to do this already. I had surgery twice in 2013 to install deep brain stimulators. The surgeries were simple but my recovery took a long time to complete. After my January surgery that affected my right brain and left body. It took us until just before my June surgery to get the settings right. So I walked freely, on my own for almost a week. After my June surgery, which affected my left brain and right body. I had a right knee riddled with arthritis. I had to suspend walking training to replace my knee. Now 2014 is behind me. Now my knee is healthy. Now I am ready. It is time to walk.

April 7, 2015

My son, the big red one, and the smallest tulip.

A few years ago, when I still felt like I could travel, and when Clark was in kindergarten, I took him on a trip for spring break to Washington D.C. where we visited my sister. The entire city was beautiful. Spring was in full command of the weather. Among the things we particularly enjoyed were the large planting of tulips.

Near the White House, close to the National Mall, there was a large patch of tulips in the shape of the numeral one. They were all red. They represented the First Infantry Division of the U.S. Army. Its nickname is "The Big Red One.

Saturday is World Parkinson's Day. The anniversary of the birth of the doctor who first wrote the official description of Parkinson's disease and formally published it. A red tulip was named for Dr. Parkinson.

When I took Clark on that trip, I had Parkinson's but it was so mild back then that I could look at a field of red tulips and not think of Parkinson's at all.

Clark has always had a different perspective on the world. He looked at that big field of tulips and focused on the smallest, most misshapen plant and named it and visited with it awhile when we entered the area AND WHEN WE LEFT.

Now Clark is much older. It has been ten years since I learned I have Parkinson's disease. Parkinson's has moved from the back of my mind to the front.

I recently listened to an interview between Krista Tippett and Bruce Kramer on On Being. Bruce Kramer had ALS (also known as motor neuron disease, or Lou Gehrig's disease) for about five years before he died last month. He said that when we are able-bodied, we often give people who are visibly disabled "the look." He said this look is filled with the feeling of "I could look right through disability and I wouldn't have to face its possibility in the people I'd look through." Bruce Kramer says often attribute disabilities to "the reason I'm not disabled is I didn't do whatever it was."

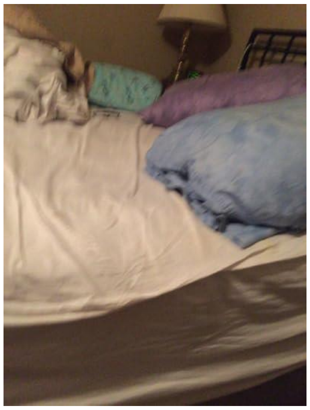
Of course he had not done a thing. No one with ALS or Parkinson's has done anything to cause or deserve their condition.

Maybe this is what Clark was seeing in that littlest flower. May we all take a moment to really see someone who is living with a disability, not just look through them. Take a moment to get past your discomfort and listen to their story.

April 10, 2015

It's Friday night. So why am I sitting on my bedroom floor? Because I have Parkinson's disease!

It has been an hour since I ended up on the floor. That feels like enough. Just a Friday night. My husband is out of town. My mother is visiting but everyone has gone to sleep. In fact I was climbing (that's the problem. I KNOW I'm supposed to sit on the edge of the bed and rotate in. Tonight I was overly ambitious and I tried to climb in). into bed when my foot slipped on my standing leg. I sank down to the floor. No. Not fell. I ended up on the floor. I tried asking for help but my voice is not very strong and my son runs a fan for white noise. This renders me functionally silent. AND I KNOW that neither my 70 year old mother or my 14 *year old son has any business trying to help me off the floor. So now I'm going to increase the voltage on my DBS, get up off the floor and go to bed for real.*



April is Parkinson's disease Awareness month.
Tomorrow April 11 is World Parkinson's Day and the anniversary of Dr. James Parkinson's birth. Since I couldn't sleep until I can correct my mistake, I decided to blog about it. That way you, too, can know some of the ways that Parkinson's can affect a daily life daily.
My bed where I want to be.

Adele posted the blog entry above to her Facebook page after midnight. A friend who also has Parkinson's Disease and who was also awake got his wife out of bed and they drove to our house. By knocking on a bedroom window they were able to awaken Adele's mom who then let them into the house to help get Adele off the floor and into bed.

April 17, 2015

Advice to Myself
As if I could write such a list by hand...

"If I knew ten years ago what I know now," is something we often tell ourselves. Some of that knowledge can only be gained through living it because when we hear it, it seems so ordinary and unnecessary that we can hardly give it our attention long enough to even hear it, much less take it to heart. Nevertheless, I'm going to share some things my life and my life with Parkinson's has taught me.

Focusing on the chronic, progressive nature of Parkinson's will only cause you to lose heart. I'm not saying to lie to yourself or to present a false face to others. I am saying that if you can focus on things that are happening right now, you'll do better.

The best gift I ever gave my husband and my son was to accept help with gratitude. I used to get so angry with myself for needing help that it seemed like I was angry with the person who was offering to help me.

Sometimes you just have to cry. Maybe you don't, but I do. My particular case of Parkinson's has a lot of non motor symptoms. I know I would be better off if I could be more patient with myself but so far I'm still learning to live with myself in a body that cannot always listen to my brain. Crying has never lasted forever, in fact it usually only lasts as long as it takes my medicine to start working.

Be kind to yourself. Negative self talk only hurts your own feelings. If you wouldn't talk like that to your mother or your child, commit to not talking like that to yourself. Parkinson's disease is hard enough. Try not to add to your burdens.

The first several years may go much easier on you than the years that come later. Don't be discouraged when your health worsens, talk to your doctor, change your cocktail of medicines. You may add years to your body's functionality.

So if you pray or if you don't, remember these words. Repeat them to yourself. They will help you get yourself through.

Today (It can be overwhelming to think too far ahead. Stay with today).

Now. Here. This. (Enjoy today for what it is. Hug your spouse. Hug your kids. Call your parents. All anyone has is today anyway.)

Be kind to yourself. (You and your family will be so glad.)

This too shall pass. (Crying won't last forever. Nothing does.)

April 29, 2015

It IS going to be better than this.
Parkinson's disease awareness month draws to a close tomorrow but Parkinson's will still be here. This has been a particularly rough month. I think it is no exaggeration to say that the last time I cried this much, I was an infant. My speech is unclear. I keep having trouble getting up when I have been sitting and I keep having trouble pulling up my pants.
Then, this evening, I realized that maybe what's been wrong is that I have been "off." I've been conservative with my Deep Brain Stimulation settings. Because I have not wanted to injure myself with out-of-control dyskinesia, maybe too conservative.
Ha ha! I turned my voltage up and I have not cried for over three hours! That's a relief!

May 16, 2015

On this day in 1987, 28 years ago, Frank Hensley and I were married the day after our college graduation. I should have suspected from the capable way he fixed my truck, after it threw a rod during a trip to Fort Worth and stranded us at '"Darlene's Motel Restaurant $19.95 and up" that he was a remarkable man. I was in love. I was marrying my best friend in the world. It is only in recent years, when I have had such struggles because of my Parkinson's that I can see it. I am married to a man of profound kindness. Frank your strength, resilience, and willingness to "fix stuff" are unmatched. On our anniversary, I salute you, I thank you, I love you.

Adele wrote me the following poem to celebrate one of our wedding anniversaries, sometime around 2015. Sadly, I don't know for sure which year. Of all her poetry to me, this has to be my favorite.

Delly's (less than stately) sonnet to Frank

A life awash in frogs and snakes and snails
might seem a grubby boy's fantasy
that leaves a girl to stand by holding out collecting pails
and wond'ring, (when her girlfriends ask) "Why me?"
But I remember oak toads in the rain
and cottonmouths that never lost their cool
and probing mud for bog turtles time and time again,
and salamanders spotted in Duke Forest's winter pool.
Being out in nature is the nature
of our love. We're in balance when we're outside breathing in
fresh air and sunlight. They inspire us. We can face each day sure
we've more nature to discover--let's begin!
Spice and sugar turned out to be made of snips and snails.
Our hearts beat faster when we think "Chuckwallas with orange tails!"

I did my Ph.D. dissertation on tadpoles because I fell in love with frogs the summer after second grade when my parents built us a house on a riverbank. I have loved snakes just as long. And, of course, snails played a huge role in our memory of that night in 1986 when she went snail collecting in a dress! The rest of this sonnet makes references to specific events with Oak Toads (*Anaxyrus quercicus*)in South Carolina, and Spotted Salamanders (*Ambystoma maculatum*) that we "spotted" in North Carolina.

Frank Hensley to [group]

June 2015

Hey folks, I'm sharing a bit of bright news. In the church foyer yesterday morning Adele handed me her walker and walked herself down to our 3rd row seats completely unassisted. No, not a miracle...just 2 years of adjustments to her DBS and medications finally coming together well. She's hopeful to finally get completely off using the walker over the next few weeks, with good therapy and practice.

I hope you all are having some brightness and hope in your lives!

Frank Hensley to [group]

July 2015

I took Adele to New Orleans today to see her MDS. Shortest, best visit yet. Since her DBS adjustment 3 weeks ago, plus 2 weeks back on Amantadine, she has better balance, feet have stopped freezing, and crying is almost gone. She's walking better than any time since her second DBS. Doc talked to us for about 15 minutes, bumped up the Amantadine dose and asked when she wants to see him again. They agreed on 3 months, which is pretty darn long for us. Overall, an excellent visit.

Frank Hensley to [group]

July 2015

This morning Adele asked me to mail some of her poems to a friend. She had me get her an envelope so she could write the address on it. I knew she would not be able to write it legibly, but I foolishly just gave her one envelope. She just posted on Facebook that she destroyed 16 envelopes before getting one good one. When I picked her up to take her for a haircut, I re-wrote the address and taped mine over her "good" one (which nobody at the post office could possibly have read). Now I have 16 other envelopes that will have to have labels taped over them if they are ever to be used for anything... I know this is a tiny thing, but isn't just the kind of tiny thing that Parkinsons piles on us all?

September 2015

Apathetic or just Distracted?

I am all alone again.
The lonely hours S-t-r-e-t-c-h before me
like an ironic red carpet.
I am free
To Do
whatever
I Can
Persuade myself to care about.
I don't know if this is apathy
or if I've simply been so distracted
by the changes to my medication
that I've had very little time to spare for
focused concentration.
All I know is I'm alone a lot
and there are times when taking care of myself
takes everything I've got.

Frank Hensley to [group]
November 2015
My wife says, "Can you help me?" all the time. I'm fascinated by this. She is a word game wizard (don't try to play Boggle with her). She's a published author. She scored a perfect 800 on the GRE verbal exam. But she doesn't ask "Would you help me?" anymore; she says "Can" instead. Because of PD, all tasks are things that she doubts can be done...

Frank Hensley to [group]
December 2015
3 nights in a row of terrible sleep... I can't get more than 90 minutes without being woken up to help her roll over, go to the bathroom, change clothes, etc. etc. I have two final exams to give tomorrow, and they are not ready!

Frank Hensley to [group]
December 2015
I've got a great idea for a new reality-cooking-comedy show: PWP+ Care Partner cook a meal together. Points for finishing in less than 2 hours, breaking fewer than 2 glass items, 3 or fewer large spills. Bonus points if you can get a teenager to eat the final product. Points lost for burns to the food or the cooks, falls, and harsh words. I think tonight Adele and I were the team to beat, but the shattered bottle of Tabasco was not impressive to the judges.

XI. Down Came an Angel

2016

Frank Hensley to [group]

February 2016

PD dyskinesia plus a touch screen = not a good match. She accidentally opens apps, posts stuff, sends emojis and stickers all the time. Of course, PD plus voice recognition is no better. She's spent the last 30 minutes repeating the same 8-words to her phone over and over, but the phone can't understand her. All our wonderful tech and no way for PWP to communicate. But what really stands out to me is when medical professionals just nod their heads like they understood and I know for a fact they didn't, but they don't ask her to repeat or ask me to translate. It's a cruel, crappy disease.

Frank Hensley to [group]

February 2016

A little while ago a friend from church messaged my wife, offering to come over and help out with dishes, laundry, or whatever needs doing. I'm so thrilled, and at the same time I'm scrambling around trying to clean up the most disgusting messes because I don't want to gross out our friend. I won't even begin to describe the state of housekeeping I maintain because I'm afraid that even you folks will be disgusted...

In spring 2016, Adele was spending her days home alone. She was walking using a walker, and at risk of falling all the time. She took a few falls where she would end up on the floor, not badly hurt, but unable to get herself up again. On a couple of occasions that was the situation that Clark came home to after school. That scared and troubled him. If she could reach her phone, she would text or call me to tell me she needed help, and I would leave work and come to her rescue as soon as possible.

Frank Hensley to [group]

February 2016

Just got back to work from home....she fell and couldn't get up. 30 minutes until my lab starts and I'm NOT ready. She's OK but I'm WAY behind...

This is the context when Claire entered our lives. Claire was a student in one of my classes, studying to become an Occupational Therapist (a goal she has now achieved!). Here's how Claire tells the story of meeting Adele:

> Five months after losing Mrs. Adele, I found a journal from my senior year of college. I was giddy to find two reflections I had not yet read about my precious friend. In one of the entries, I wrote of how, after four years of dancing side by side on Monday nights, the ending of our time together felt impossibly heavy. I shared that thought with a friend, and she urged me to keep writing as I processed that ending. She told me that through writing, I could "make the invisible visible."
>
> When Dr. Hensley asked me to write down the story of the start to our friendship in my own words, I took some time to do so. Having a tangible *something* I could do for Dr. Hensley for the first time in a very long time was significant to me, as insignificant as it may really be. It also felt difficult. To make the invisible visible, to tell this story with what feels like some finality, to find a way to write of the immense love and gratitude I feel for Mrs. Adele, felt vulnerable.
>
> Mrs. Adele wrote to make the invisible visible, and she did it so well. She used her gift for writing, for crafting lyrical stories with passion and beauty, to educate and give hope and illustrate what life with Parkinson's -invisible to so many- is like. She shared them generously; I remember asking for her poetry and receiving the unedited, raw copies just days after meeting her. So in the spirit of her, I wrote. And, in the spirit of her never-monosyllabic-replies, no matter how off she was, I have written more than Dr. Hensley probably wanted. But I think Mrs. Adele would approve.

***

Conner, then a sophomore pre-med student, was a source of wisdom for the classes I took across campus from Jennings. I trusted him because he too was touched by disability - his brother had SMA. Because of our disability connection [Claire's two brothers have cerebral palsy], we somehow got connected, and I asked him all my STEM questions. When the time came to register for BIO 112, I asked Conner who I should take. He told me that Dr. Stark and Dr. Hensley were both great. He thought that I might like Dr. Hensley because his wife had a disability, but his tests would be harder. I believed, and still do, that people affected by disability are always worth knowing, so I decided to sign up for Dr. Hensley's class. Well, I signed up for his lab. I have to be honest here: I was a little too scared to sign up for his lecture with Conner's review! (the truth comes out! ha).

I remember our first lab meeting, where he told us that his wife has Parkinson's, so he keeps his phone on him in case she needs anything. Though our situations were vastly different, I understood. I could imagine his world, the juggling of responsibilities; I recognized it.

One day, maybe even the next lab, Mr. Kazery sat behind me and asked Dr. H, "how's home?". I heard Dr. Hensley share a story from earlier in the week where Mrs. Adele had fallen right before Dr. Hensley had a meeting with a student. She had texted him and told him that she could wait for help, that he should meet with the student first; she would be okay.

I was floored. Who was this woman who was sacrificing so much for the sake of our education? I was supposed to be focusing on our lab assignment, but I couldn't help but think of this incredible woman and wish that I could know her; wonder if there was anything I could do to help. I was a freshman with a pretty wide-open schedule: I knew nothing about

Parkinson’s, but began wondering if I could offer to help her up when she fell. Maybe we could be in a text group together and if Dr. Hensley wasn’t free I could go? I thought about that for the rest of lab. (Thank goodness the Hensleys had a better idea than that!).

As I walked out of the lab, I hesitated at the door. Should I offer? I ended up walking right out, too scared that he would think I was brown nosing in search of a good grade in a course I didn’t feel confident in.

Early in the semester (all of these events had to be fairly close together as our first day at dance was March 1st), Dr. Hensley gave a presentation on nature photography for extra credit. As I entered the nature center, I saw a woman with salt-and-pepper hair and bright blue glasses slipping down her nose sitting in the front row. She sat on a chair with her walker in front of her, looking unsteady, but beside her was a young boy with Dr. Hensley’s face who lovingly patted her arm. She laughed and commented throughout the presentation, and I wished I could speak to her afterward. I thought again about offering to help, but I was too embarrassed. It seemed so presumptuous of me to even think that they might want my help - I couldn’t do it.

As I was beginning BIO 112, I was also a brand-new member of the Catholic Student Association. I knew next to nothing about liturgy, having grown up in a range of non-denominational churches, and had never before observed Lent. This year, however, at the urging of my friend Taylor, I decided to give it a try. There was only one problem: I had no idea what to give up. While I was both debating offering to help my professor and wondering what to give up for Lent, I read the Pope’s Lenten address. It spoke to me: he urged all followers of Christ to give up indifference. As I read his words, it hit me: my trepidation to offer to help Dr. Hensley and his wife was an act of indifference, purely out of fear for what my professor may think. I prayed and thought about it for about 60 seconds before I gathered enough courage to walk across campus and proceed into his office, armed with questions for the upcoming exam (my visit had to look legitimate!), and my "Both my brothers have Cerebral Palsy so somehow that makes me qualified to offer to help your wife with Parkinson's though I actually know nothing about Parkinson's" speech.

I still remember how nervous I was as I sat in one of those leather chairs in his office. I remember he looked surprised. I don't remember exactly what I said, just something vague about my brothers and how I could help if they needed anything? The first thing he said was, "Well that is very sweet of you…" But he told me that he took off for her doctor appointments so he thinks they were okay. I felt my face getting red as I stood up, but he asked if I had a car. I nodded, maybe too enthusiastically, and told him it is a jeep. Before he could shake his head at the lack of accessibility, I rushed to tell him that we bought it for my brother so it is very low to the ground - I could even drive it up to Hederman so he could look at it! I wonder now what he thought of such an overeager freshman, offering up solutions before he could even say a word. He said that was good to know, that he may take me up on it one day, thank you again.

I was disappointed, but glad I finally found the courage to say something.

I can't remember the next time I walked past his office, but it must have been within that same week or so, and I remember that it was to pick something up outside his other office next door. I walked past his open door to grab the papers, and he called me in. I didn't sit down, but was standing in front of the chair where I sat and sweated the last time I was there. He told me he might take me up on my offer, that there is a dance class his wife wanted to go to, and she needed someone to drive her. I fairly squealed with joy and his eyebrows shot up. "Really? I didn't expect you to be so excited." (oh, would he come to see how excitable I could be… 😊.)

He couldn’t have known that a dance class was the reason I was sitting in his biology lab, pursuing OT school. I was thrilled. I practically skipped my way out of Hederman and called my mom on my walk home, telling her she would never believe that I was going to get to go to a dance class for people with Parkinson’s starting the next week.

Though I had a lab exam that next Tuesday, I spent all weekend reading anything and everything I could find on PD, watching videos of dance classes, and ensuring I was as prepared as I could possibly be so that this wonderful woman who I already loved (though I could not, at that moment, even begin to imagine how much I would go on to love her) would feel safe, well cared for, and have a wonderful time.

***

That is the end of the “before meeting Mrs. Adele” part of the story. I would love to know what happened on the other side, because I always imagined Dr. Hensley going home and relaying the story to her, telling her that he told me they didn’t need anything, and her immediately suggesting dance class. I love to think of the sparkle in her eyes as she invented the plan which would go on to be the beginning of one of the most significant relationships of my life.

That’s all that Dr. Hensley asked me for, but I want to keep writing, because I want to share a little more about our first night together, part of the story that he may not know.

***

My heart raced as I knocked on their door, reading a sticky note about the doorbell and their dog. Mrs. Adele opened the door in bright red pajamas, with Gryff at her side. She welcomed me in, talking quickly and quietly, and I leaned in to understand. She pointed to a low table in the living room and asked if I could take her credit card which was out on the table and register for the class while she finished getting dressed. I nodded, and we went our separate ways: me to register for the class, and her to get dressed. I felt a little sheepish, pacing between the bedroom she had disappeared into and the living room, wondering if I should have offered to help her? Was she okay in there? Was Dr. Hensley going to be home any minute and find me standing in their living room with his wife's credit card? I was so unsure of myself and my role there. It is so strange to think back to how out of place I felt, when now, so many years later, that living room feels like home. I remember when she came out of the bathroom and sat down in a chair in their bedroom to put her socks and shoes on, I felt like I should help but wasn't sure how to go about it. I asked if she needed help, and she said it would go faster if I helped her, but I didn't understand her words, and didn't yet know what to do when I didn't understand her, so I awkwardly patted Gryff for a few moments before asking again if she wanted help with her socks (I am ashamed of myself now!!). She graciously repeated herself, and this time I understood, and pulled them on. I remember wondering what she was thinking at that moment. I was so incompetent, so uncertain, and she was so…resilient. Patient. Kind. Strong - physically strong. I remember being terrified when she asked me to set her walker down at the bottom of their garage stairs and she climbed down those steep steps by herself. She was incredible. By the time we got into my car, sweat speckled around the curls at her temples. Yet she had the kindness to turn the conversation to me immediately. She smiled as she turned to me, "So, where are you from?" As I wrote not long after that first night: "It was insanely beautiful the way we embarked as strangers, but as we stepped through the doors of Millsaps's athletic facility felt like such a team, an unbeatable duo. Somehow an hour was enough, and God ordained a most beautiful friendship that has blessed my semester and will continue to bless my life."

I know so little of her perspective on that night, and I wish now that I had asked her more details about how she felt in those moments when we were so new to each other. I do know she wrote a Facebook post that Sharonda tagged me in:

“Tonight I went back to Dance with Parkinson's class at Millsaps College for the first time since I stopped driving myself. In all this time I never found someone who could drive me. Last week a student Came up to Frank, introduced herself and explained she was

A triplet whose two brothers have cerebral palsy. One brother goes to Millsaps one goes to Belhaven. And then she said "Dr. Hensley, if your wife needs anything, I'd be happy help her." Seeing the possibility he asked if she could take me to dance class. She did and we had a great time.”

I did not know until tonight, when I was searching for that exact Facebook post, that she had posted in 2013 asking for someone to drive her to that class. It took 3 years. Man. No one was as patient as Mrs. Adele.

18 year old Claire could not know just how great of a blessing Mrs. Adele, her family, and those Mondays at Millsaps would go on to be. The patience, grace, kindness, and infinite belief in me that Mrs. Adele showed me that first Monday continued to be themes throughout my time by her side.

Even as an unsure, anxious freshman in college, she saw me as capable, she reached out to me with hands that trusted I would not let her fall (and continued to trust me and forgive me even after we did have falls), she spoke truth into me and encouraged me along every step of college, of my journey to become an OT.

The week that I graduated, I perched on the toilet beside her as she sat in front of the sink and brushed her teeth one night. We were savoring every final moment we had together before I moved to Delaware. She took every moment she could to encourage me, speaking truth into me: you will be an amazing OT. You can do this. The week before, she had told me I should create my own version of the reflector bands we put on her ankles to keep her pajama pants from tripping her; she told me I could call them “angel bands”. I loved the way she believed I could do, be, create anything. I tried to see myself the way she saw me.

Claire’s graduation from Mississippi College, May 2020

This night, she looked at me and told me that I have an energy inside me that lights up a whole room; that people with Parkinson’s need that. She encouraged me to go be for someone else what I have been for her; to make a difference for them, too. She started crying then, and I wrapped my arms around her and breathed through my own tears. I told her I just love her. I don’t want to do anything for anyone else; I just love her. She wouldn’t let me. She wouldn’t accept that as an answer. She saw so much in me, she believed so much in me.

What started as a simple offer to help my biology professor became one of the greatest gifts of my life. I gained not just a friend whose impact on my life will be eternal, but a family, and memories with all of the Hensleys that I will never take for granted. When Mrs. Adele died, Taylor told me that she hoped I could find some peace in knowing that, at least, Mrs. Adele and I were the kind of friends who never left anything unspoken. We both knew how much we meant to each other. And though that has done nothing to

> dull the ache of the loss of such a celestial soul, I cannot deny the truth of it: Mrs. Adele and I hugged tightly, really listened to each other, laughed, cried and spent as many hours together as we could stay awake for. This kind of friendship is once in a lifetime, and I will always be thankful for Conner, BIO 112, and one lab conversation that gave it to me.

Frank Hensley to [group]

February 2016

What a day we've had. We had the alarm set for 5:00 AM but she got up to go potty about 4:00 and I never got back to sleep. Reported to the hospital at 7:00 for her incontinence procedure. It's a 15-minute thing. We sat 3 hours before they called us back, then 2 more hours before they took her to surgery. The only good part was that the IV went in on the first try, and that never happens for her. After surgery the anesthesiology nurse actually turned her DBS back on right away (THANK YOU!). But then constipation issues made her decide she couldn't go home yet, so she spent two hours in the bathroom at the hospital. Meanwhile I texted a friend to arrange for someone to pick our son up at school since we were much later than I planned. Unfortunately, due to miscommunication between teens and forgetful parents, the kid I was counting on to drive my son home wasn't even at school and didn't have his phone. Our son doesn't have a phone, so he was stuck at school with no ride and no way to call anyone. Meanwhile we stopped to pick up antibiotics and supper... and the car battery died. So, once I found out that my son was still at school, I had no way to go get him. I posted a plea for help on Facebook, and the troops came out in force. Multiple people came to our rescue or offered to help. We're home safe and sound with full bellies. But I'm totally exhausted. And if you've read this far, now you are too. Sorry 'bout that.

Frank Hensley to [group]

February 2016

Did anyone's PWP spend 30 minutes face down on the floor of a gas station bathroom yesterday? Anyone? Anyone?

Frank Hensley to [group]

March 2016

I'm looking for advice... my wife's PD seems to have reached the point that it is no longer safe to leave her home alone. In the last 3 weeks she has fallen about a dozen times. This week she fell 3 times when I was at work. She managed to get herself up just once. Two times she had to wait for help to come home. I also came home one day to find her stuck on one side of the room with her pills, but no water to drink (and Rytary capsules are HUGE). She couldn't safely get up and cross the room to where her water was. So, she was 2 hours late for pills, crying, with wet pants...

Today when she fell, her phone battery was dead. So, I didn't know she was in trouble. But even with a working phone she has a terrible time sending messages or calling.

So...I need to think about hiring someone to stay with her, or taking her to adult day care, or even taking her to work with me.

She has long-term care insurance but as I read the policy it has a 5-year limit; once we invoke the benefits, they end in 5 years whether she has used the maximum dollar value or not. Well 5 years just isn't enough for a 50-year-old PD patient.

So, I'm not sure what to do...

Thoughts? Advice? Ideas I haven't considered?

Frank Hensley to [group]

March 2016

Yesterday she said she thinks she has cognitive issues. Nobody has ever said that out loud, but I've been thinking about it for a few months. Tonight, our son is on an overnight bus ride to Disney World with the school band. Well about an hour ago my phone rang...1:30 AM. Of course, I'm instantly scared. I fumbled answering the call for 3 or 4 rings and when I did nobody was there. Caller ID said the call was from an unknown number in Texas. Her response to all this? She had me help her to the bathroom and now she's back to sleep. It apparently didn't even register with her that he's on a bus somewhere in Florida and this could be an emergency. She asked if it was time to get up like the call was my morning alarm. Anyone else think her lack of concern could be a sign of *cognitive issues from PD? Anyone think I'll get back to sleep? The band's Facebook page is silent...*

Frank Hensley to [group]
March 2016
GRRRRR! She's in the rehab hospital using an unsecured WI-FI connection, accepted a friend request from a fireman in our church (but it was actually a hacker), and then proceeded to fall for his offer of grant money for disabled people. Gave him her full legal name and sent an e-mail to an address he gave her. I don't know what she put in the e-mail... She never would have fallen for such 5 years ago...

April 2016

The Shiner

I took a fall on Monday.
Like I hope you never will.
It was something like a tumble
It was much more than a spill.
As I stepped up to the scale in the large inviting space,
I landed with a crash. You see, I fell upon my face.
I smashed my orbit and my cheekbone into the hard unyielding scale,
I had to sit a minute. I caught my breath. There was no time to wail
I was suddenly surrounded by all the people who worked there.
A nurse who heard the noise brought me ice and a wheelchair.
The nurse who helped me get up also took my vitals.
He really was unflappable, without any rivals
My own nurse was kind of flustered.
When my nurse came back, her mettle she had mustered.
When I fell, she was standing close by but I turned from my walker to the scale so fast
that no one could have stopped my fall. It was done as quickly as it started, the first moment to the last.
For the next two days, the bruise was deep. I saw no signs of color.
I didn't want to think about how this fall differed the others.
I thought I got away with falling without any bruising.
I thought I would not have to answer questions, that were not of my choosing.
It was not to be. This was a different kind of fall but one that couldn't be ignored.
It stood for the progressive nature of the Parkinson's, not side effects. I was feeling floored,
Two days later, on Wednesday, my cheek began to bruise.
By evening, it appeared, like the first crescent moon in the sky,
I sported a slim shiner by my eye.
I never had any ambitions to be a hero.
They score for the week is Parkinson's 1: Me 0

May 2016

Adele had her other knee replaced. The last time, we had Thanksgiving dinner from the hospital cafeteria. This time, we had our wedding anniversary dinner in her hospital room, but I went and picked up very good food from a local restaurant.

Frank Hensley to [group]

June 2016

Made an appointment with an elder law attorney and dropped off a ton of paperwork for review (existing estate documents, life insurance, long-term care insurance, banking, retirement account, etc. etc.) I'm optimistic that this guy is going to help us develop a plan that maximizes our resources for Adele's increasing needs. It's clear to me that unless this week's DBS programming does amazing things, she's got to have an attendant every day that I'm at work this fall (or go to a daycare or something). My next step will be to find out the costs for the two local adult daycares vs. costs for the two local home health aide services. I'm worried that I can't get her to a daycare every day by 8:30 so I can teach my 9:00 class. I'm also worried about having strangers in my house, where theft of valuables and identity theft could be easy. I'm also worried that they will send some 95-pound aide who can't provide the physical strength necessary for the job. But right now, just knowing that we have the appointment with the lawyer is making me feel SO much better. Sleep might be more possible when there is time to try. Today we have clarinet lesson for the kid, eye exams for both of us, then I'm taking her to Bible study that she co-leads at the Methodist Children's Home, and then to Parkinson's dance class. Exhaustion, here I come again...wait, I never left.

Frank Hensley to [group]

June 2016

She wants to go to the big national PD conference in September in Portland. She sent in an abstract to make a poster presentation, and it was accepted. She applied for a travel grant and got her airfare covered. She can't travel alone. She can't go 4 hours without a bathroom break. She can't get into and out of an airplane bathroom. She can't walk more than 10 feet. She can't stand up without assistance. She can't get up if she falls, and she falls about once per day. I have to work when the conference is going on. She's trying to recruit a friend or family member to take her to Portland, but none of them have any idea how disabled she has become. If I didn't have to work then, I'd have to tell her no, and I'm the best prepared person to take her. Nobody else can manage it. But she's in denial...she's looking for hotel rooms...I'm afraid she's going to spend money for plane tickets for two people and then not be able to go... OK...I'm done. Back to our regular lives now. Sorry.

Frank Hensley to [group]

June 2016

And now for something completely different... she saw her Neuro in New Orleans on Wednesday and he says he's running out of options and ideas. So, the second week of July we will go to the hospital and stay all week, seeing him and/or his NP for programming sessions several times per day. I don't think we can stay with her sister in N.O. that week because the wheelchair won't go through the bathroom and bedroom doors. So, we'll stay at the hotel that is at the hospital. It's just 5 minutes from the hotel to the clinic. Perhaps if they adjust her DBS several times, we can get her back to walking...

Frank Hensley to [group]

June 2016

I had a really encouraging meeting with the elder law attorney. I have always assumed that PD would force us to go broke sooner or later and that I'd have to burn through all my retirement money and lose the house just to provide for her care. I learned things are not nearly so grim. To get Medicaid to pay for nursing home care, the PWP can't have more than $4000 in assets, but the spouse can have $120,000 plus a house, car, and contents of the home. So, she can be broke in a nursing home and I can still have a middle-class existence. Beyond that, the attorney looked at her long-term care insurance policy and liked what he saw...he explained some things I didn't understand. It looks like I can hire help this fall and get most or all of the cost covered by insurance, and we can transition to Medicaid paying for some of her care in about a year or so, preserving her long-term care insurance and stretching it out for more time. We can actually set up trusts so that even if we both die broke in nursing homes, our kid can still have a chance to inherit something...even the house and life insurance payout. I had no idea that much of this was possible. So, I'm spending the $3500 to get new wills/power of attorney/trusts etc. all set up, and then transferring stuff out of her name to either my name or to trusts. I'm feeling very positive compared to where I was. We were very lucky (blessed by God) that she qualified to buy long-term-care insurance, but even if we didn't have that, we'd still have hope of Medicaid covering much of her care for years to come. So, whether you have that kind of insurance or not, I'd strongly encourage you to seek out a good elder law attorney sooner rather than later.

Frank Hensley to [group]

July 2016

We are in New Orleans for a week of intensive DBS reprogramming. We got here last night hoping to start first thing this morning, but our appointment wasn't until 1:00. At 1:00 the Neurologist's Nurse Practitioner came out and said the Neuro is quadruple-booked and we need to come back at 3:00. That's frustrating. But she also said that they have a plan...they are going to re-map Adele's DBS starting like it was a brand-new implant. We'll do one side this afternoon, the other in the morning, and then begin adjusting from there *through the rest of the week... We are both very encouraged by this because this NP has a reputation of being a skilled programmer and she was not here when Adele first had her implant surgeries so she's a fresh set of eyes...I'll let you know how things go. The other good news is that they don't want her to be totally off medicine. She's going to take about half her regular Sinemet at 2:00 so she's pretty close to unmedicated at 3:00... I'll try to post an update later and let you all know how this goes.*

…

Doc switched her to a different program expecting her left side to respond.
Instead, she became wildly dyskinetic on her RIGHT side.
Make that VIOLENT dyskinesia. Almost threw herself out of the chair.

…

So, we had an 8:00 appt. with the Nurse Practitioner who does DBS programming, but the Movement Disorder Neurologist joined in. They reviewed Adele's case for the last 3/12 years, discussed each change to her DBS and why it was made, and then tried to come up with a plan. But that spun into a discussion of DBS theory and how voltage, current, pulse width, and pulse frequency interact. Eventually Adele asked me to go to the bathroom...when we got back there was a second MDS and the new MDS fellow all in the room conversing about theory. It's hard to feel you're not getting good medical care when you have 3 MD's and a nurse with a doctorate all in the room working on you. Eventually they agreed on a plan and all the MD's left. The NP made electronic changes, told us how much PD medicine she wants Adele to take, and sent us away. We go back at 2:15 to see how things look. If Adele doesn't end up with better DBS settings by the end of the week, it won't be for lack of effort!

…

No time for details. Short version: lying on hotel bathroom floor wildly dyskinetic and covered in vomit. Not a good afternoon. But now we are sitting calmly in the neuro exam room discussing what works and what doesn't. Roller coaster called Parkinson's.

[After lunch we went to our hotel room, and the dyskinesia increased exponentially. She fell in the bathroom. She was lying on the floor banging her head against the toilet. I pulled her away, so she'd stop hitting her head, and went for some pillows. But she was wedged in the bathroom, and I couldn't get her out. I needed help to get her up. I was desperate. The hotel is physically attached to the hospital… hundreds of medical professionals just down the hall, but the hotel desk and the hospital switchboard both refused to send anyone. They told me to call 911. I was about to do that when a passing security guard took pity and helped me get her into her wheelchair. When we didn't show up for our 2:15, and I didn't answer my phone, the Nurse Practitioner actually left the clinic and came to our hotel room looking for us.]

…

Peaceful now. The hotel room smells fresh. No dyskinesia. We go back at 8:00. We are experimenting tonight with a narrower pulse width on the stimulators to see if walking and/or speech are improved. No PD meds after 4:30 AM so she's OFF when we get there at 8:00.
This evening has been very good, after a hellish day. But we think the docs learned a lot about what NOT to do to Adele's brain...and that's important.

…

Yesterday they had her come in off medicine, and only take her Carbidopa-Levodopa during the day. She had essentially the same DBS settings we started the week with except the pulse width was narrowed from 260 to 210. We stayed in the same exam room from 8:00-5:30 except for a 1-hour trip to the hospital cafeteria for lunch. She never really turned ON until the 4th dose of the day, after a voltage boost. But that ON was really good. So today we are doing her full regular medications and those DBS settings. We saw the Nurse Practitioner at 8:30 and she cut us loose until 4:45. But we can't really go anywhere because the speech clinic is trying to work her into the schedule, and so is the neurosurgery department - she's got to have a new DBS battery in the next 90 days. We've exhausted the hospital's entertainment options (gift shop) but Adele's sister is coming to eat lunch with us...

Yesterday's hours upon hours of OFF time were hard for both of us, but two key moments stood out for me. At one point she said something like "You don't really care for me at all, and you never listen to me." That really stung because ALL I've done since May 12 is stick close and listen carefully trying to understand what *she needs. Of course, it was just the low dopamine talking, but still she's never descended to that level. I know many PWP become angry and abusive so some of you take a lot of emotional beatings that I've never had, but this was a painful first. The other thing that was hard was when the MDS was introducing her case to his new MDS Fellow and described it as "advanced Parkinson's, young onset." I've never heard him say "advanced" before and that was hard to hear.*

…

I've lost count...we've had 15-17 separate sessions with the MDS and/or his NP this week. Plus, we met with the surgery scheduler. And we are now waiting on the ENT to evaluate her breathing. What a LONG week!

Frank Hensley to [group]

July 2016

Care partner confession: She put her pants on all by herself (yay!), but they are inside out. I didn't tell her.

Frank Hensley to [group]

August 2016

8 weeks ago, about 2 weeks after knee replacement, Adele could barely stand and was using a wheelchair for all of her mobility. Today at her final session of LSVT BIG therapy she walked with a completely normal gait using her walker. So, knee replacement plus DBS programming plus LSVT plus time to heal has all added up to a huge improvement. Parkinsons wins the war sooner or later, but right now this battle is OURS!

Frank Hensley to [group]

August 2016

When I got home today Adele had had a shower without me, lunch without me, done her LSVT exercises without me, the kitchen was clean, the dishes were done, the bathrooms were clean, and all the laundry was washed. And I didn't do any of it. I think I like having a paid caregiver come to our house. (Ask me again in 2 weeks when the bill comes...).

Frank Hensley to [group]

August 2016

At the hotel... Adele is supposed to take 2 showers with antibacterial soap between now and 5:AM. Of course, the hotel had no rooms with a handicapped shower even though I specifically reserved one.

Frank Hensley to [group]

August 2016

Update...Sorry this long. Yesterday Adele got a new pulse generator (battery) for her DBS. Thursday night we stayed up too late because her sister dropped by the hotel to catch us up on flood recovery stories from her parents' house. We had to get up at 3:45 so Adele could shower before her 5:AM report for surgery. Well between 11:00 PM and 3:45 she got up at least once per hour. The surgery was routine, and Dr. Smith told me she'd be ready to go home about noon. But he told the recovery room not to give her the IV antibiotics until noon, so we were almost 1:00 getting out of there. I knew she was hungry since she'd had no breakfast and just a small turkey sandwich in recovery, so we hit the hospital cafeteria. She ordered a huge meal and then took almost 2 hours to eat it (while I repeatedly but gently reminded her that I was exhausted and the longer we delayed our departure the more difficult the drive would be). So finally, we left the cafeteria. We hit one of the 1-person ladies' rooms only to find it occupied. So, I took her to the Men's room (she hates that) but it's also a 1-person unit so what's the difference? We got into the car, but she wanted to finish a Facebook post from her iPad, so she asked me not to leave the Wi-Fi area yet...So 10 minutes later I took over typing, finished her update, and we hit the road. We went less than 4 miles but just as I pulled onto the interstate ramp, she asked to go potty again. Well, I-10 through New Orleans is a challenging traffic situation, and I don't know of any 1-person bathrooms we can both go in, so I made her wait....almost to the Mississippi state line. We hit a Popeyes restaurant, and in record time (about 5 minutes) did the wheelchair/walker/ladies room/back to car routine. Great! No delay! Grabbed a tank of gas...13 miles to Mississippi. Before we hit the state line, she asked to go potty again... The Mississippi Welcome Center has a ladies' room with a big garage-door type divider so they can close off half of it for us and I can go in with her, but the other half is open *for other ladies. Except that option is not available after 5 PM. We got there at 4:58 and they wouldn't let us do that. So, she had to go to the regular ladies' room by herself. Oh, did I mention the rain was coming down in buckets, so getting out of the car and into the wheelchair we both got soaked? So, she went to the ladies' room alone... for an hour. We finally got back on the road, and then she wanted a snack... It was after 6 PM. So, a snack stop had to be made. Got home at 8:PM. I fell asleep on the sofa by 9:00. At 11:00 she woke me up to take her to the bedroom...I was basically comatose all night except sometime between 2 AM and 3 AM when she fell in the bathroom. I heard her, got up, helped her up, and then went back to sleep. I'm about to go take an afternoon nap, but I thought I'd share the saga because I know you can all relate!*

XII. Portland and Beyond

August 2016

Adele loved to share her story and to connect with others. She had produced three books that addressed the emotions invoked by Parkinson's Disease, aimed at children. So, it was time to take that message on the road. The 2016 World Parkinson's Congress was set for Portland Oregon, and Adele wanted to go. I was deep in a busy fall semester of teaching, so of course I couldn't take her. But her younger sister Anne heroically stepped up. The logistics were daunting; Adele's personal care was challenging enough, but adding in airplane flights, taxi rides, hotel accessibility, and the prospect of getting her presentation together made it an enormous undertaking. And just to make things interesting, Adele was invited to make an oral presentation in addition to the poster she had planned. How would she handle that, with her vocal symptoms? Claire to the rescue! Claire read and recorded much of what Adele wanted to say, so that Adele's message was sure to be heard.

I got an email last night from
Eli Pollard executive director of the 4th World Parkinson's Congress inviting me.to give a hot topics seminar (so talk for ten
Minutes
between. 8 and 9 am to the delegates coming to
The General session.). This seminar is based on my abstract for my poster. I wrote the Abstract in the hopes that it would make me more eligible forr a travel grant. I submitted it the last dAy it was supposed to.be. accepted. On the off chance that it wound be eligible, I checked the boxes to indicate my willingness to be part of a poster tour and a hot topics talk. Surprisingly, it has been accepted for every category I've put it up for. I am dumbfounded. Anne Pfrimmer I think if better order the tickets for the Jackson ro Portland leg of the trip today. Ok?

Frank Hensley to [group]

August 2016

I love that crazy girl...Adele is presenting a poster at the World Parkinson's Congress in Portland about books for kids about PD. And the organizers asked her to give a talk, too. Keep in mind that half the time I have to ask her to repeat herself, and she's doing daily LSVT speech therapy. But she said yes to giving a talk. What???!!!??? She's nuts. But GO ADELE! I'm proud that she's going to go there, and try to do it, even if nobody can understand a word she says.

Frank Hensley to [group]

September 2016

My stress today: The World Parkinsons Congress starts tomorrow in Portland. Now, Adele is incontinent, you know. So, we decided she should wear an adult diaper on the plane, plus sit on a disposable bed pad. She made the plane reservations without consulting me, and she scheduled just 1 hour between flights in Dallas. Most healthy people can struggle to change planes in 1 hour in DFW, but Adele was certainly going to need to change pants, too! So, when I got out of teaching my class, I tracked her phone and saw that she was in the terminal in DFW. Her phone didn't move for about 20 minutes, so I guessed she was in the ladies' room. (Cyberstalking her phone in the ladies' room feels less creepy than when I loiter outside the door of a ladies' room listening for her in case she falls and getting weird looks from all the women coming and going.) A bit later I could tell she was out of the terminal and on the plane. So, I know they made the connection. Yippee!

But the flight from DFW to Portland is 4 hours so that diaper and pad are going to be soaked. I fear she is having a difficult and humiliating experience. But she so wanted to go, and I try to support her in every way I can.

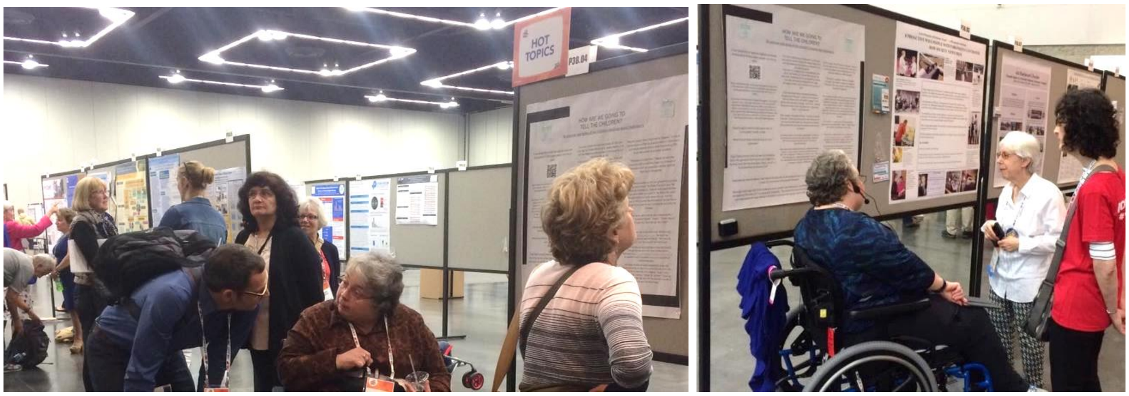
Her sister has spent no real time caring for Adele so I think she was in for a bit of shock as she figured out just how needy Adele can be.

If you're the praying type, please keep Adele and her sister in your thoughts - Adele is actually not quite done with the poster she's supposed to present on Wednesday nor the talk she is supposed to give Friday morning...

I've been up since 3:30 and I need to write an exam before I go to bed, so I better quit this and get to work!

Obsessed with our situation, but I'm pausing for a minute to say prayers for all of YOU!

Frank Hensley
September 21, 2016
I can't tell you all how proud of Adele Hensley I am right now. It takes her 10 times as much effort as it should to do something like put together a poster presentation and talk to people about it. This is what fighting Parkinson's looks like. And she does it 24/7/365.



Frank Hensley to [group]
November 2016
I took Adele to her mother yesterday so her mom could take her to her Neuro today in New Orleans. I misplaced my phone for a couple of hours tonight, so I just discovered a message from her... Apparently, she fell today and was on the floor for 2 hours. I don't know any details yet, but now I'm very sad about it.

Frank Hensley
November 2016
Except for teaching one class and doing about 30 minutes of research, all I have done today is insurance paperwork and paying bills. I'm exhausted by it! Nap time.

Frank Hensley to [group]
December 2016
My wife and I have been enjoying the TV show HOUSE on Netflix. We never watched it when it was in production, but now we are, and we really like it. But we hit an episode the other day that was a sledgehammer. The patient was a relatively young man with advancing Alzheimer's and his wife was doing full-time care. The main characters got into a discussion of whether a young person should stay with a disabled spouse or abandon them and "move on with life." One character said that if a person becomes "a burden" to family then they should just find a way to die. I tried to be cool during the scene, but inside I was screaming at the TV to shut up. Adele got pretty upset but I told her that the stupid TV writers didn't know what they were talking about, and we moved on... but it was brutal to listen to for both of us.

Frank Hensley to [group]
December 2016
And on a completely different note, from the one I just posted, Adele had a urology procedure on Friday morning to help stop leakage, and then I took her out for lunch. While she ate, she spilled/dropped about 1/4 of her food on the restaurant floor. That's a little more than usual, but she'd just had anesthesia, so I wasn't surprised at all. I tried my best to catch her spills and help her. As we got up to leave a customer at the next table looked at us and thanked me for "taking such good care of your wife." Well, that's all it took to set Adele off crying. The lady gave Adele a hug and told her she'd pray for us, and Adele just cried more.
I don't really know how to deal with such things. I used to feel very self-conscious about Adele's messy eating in public, but that was because I worked at a cafeteria in high school and heard other teens say some awful things about a regular customer who was disabled and made a huge mess at dinner every night. Finally, I decided that life is too short and stupid judgmental people aren't worth my time or emotional energy to care about . . . but this was just the opposite - Adele's mess didn't bring criticism, but it brought me praise. I don't want that either! I tried to just be gracious and help Adele gain her composure so we could walk out, but it was a difficult scene. Still, I do feel like I do a pretty darn good job as a husband and caregiver in most things. I just don't want

attention from strangers (never have). It actually felt a little intrusive - please just let us eat in peace and don't make more of a spectacle of us than we already are.

Frank Hensley to [group]

December 2016

Adele decided she really wanted to go see her parents' home, where remodeling has begun after they lost everything in the flood last fall. So, we took her. Only there's no working plumbing and the first thing she said when we got there is that she needed to go potty. So...to the porta-potty we went. Keep in mind she walks with a walker, and I have to help her with the whole bathroom process...Plus, a porta-potty is made for 1 regular sized person and together she and I tip the scales at 550. Adventures in Parkinsons!

Frank Hensley to [group]

January 2017

She's been dropping and spilling EVERYTHING lately and I've been admonishing her to stop reaching for stuff. I heard her yelp about dropping her slice of birthday cake and I got to the living room just in time to see her tumble headfirst from her wheelchair because she was trying to reach her cake before the dogs got it. She's fine but I'm frazzled. Oh, and the cake was smashed into the carpet.

Frank Hensley to [group]

January 2017

I mentioned subtle evidence of cognitive decline, and Mike asked what exactly I was seeing... little things. A couple of months ago she was lured in by advertising by a background-checking company that suggested she has an arrest record (which she does not!). So, she bought a $1 trial membership from them so she could see her background check. And they upsold her on a $1 premium membership. And 8 days later both memberships automatically "renewed" at full price. So now there's $100 worth of charges on our credit card for a useless service we don't need. And she can't figure out how to unsubscribe. And it is unclear if this is going to renew every 8 days...

Frank Hensley to [group]

February 2017

Here's her bruise from one of yesterday's TWO falls.

Well, I was napping on the couch, so she got up to let the dog in... and fell right into the dog's water bowl. Another bruise and completely soaked set of clothes. All 3 falls in the last couple of days were when she tried to walk alone.

Frank Hensley to [group]

March 2017

Adele surprised me today by agreeing to go see the eagle nest near our house. We used to go on nature dates all the time, but it has been at least 10 years since she joined me on an outing just to see nature. We spent about 45 minutes on the side of the road. I photographed the eagles a bit and socialized with two photographers I know from Facebook. Adele struggled to get binoculars to focus (a skill she never used to have any problem with). We spent about 45 minutes watching the nest, and then drove to a nearby medical clinic that she goes to where we spent about 45 minutes in the bathroom. Not the sort of date one dreams about, perhaps, but I loved seeing her out in nature for the first time in years. We both had fun.

Frank Hensley to [group]
March 2017
Adele has two Dr. appointments today. And I have one, plus a class and a lab to teach. Guess which day the caregiver was a no-show?

Frank Hensley to [group]
April 2017
When they find me dead at my desk from a brain hemorrhage, I will be on the phone with Adele's insurance company fighting for her medicines.

Frank Hensley to [group]
April 2017
I'm grumpy today. We went to bed about 10 PM but she got me up 5 times in the next four hours (twice just to roll over and 3 times to go to the bathroom). We slept uninterrupted from 2-5 AM, and then it was time to go potty again. My students better be careful this morning or I'll probably bite their heads off!

Frank Hensley to [group]
April 2017
I cannot possibly say enough R-rated words about [insurance company] right now. There is nothing on this planet I hate more than the bureaucracy of trying to get medications for my PWP! Damn the system to hell for all eternity!

May 17, 2017

Bonded.

It's funny. This anniversary has seemed to have snuck up on me, even though I've known it was coming for quite some time. I've known it was coming for quite some time. Sorry this is a day late. Sorry too that it is not a poem.
Today was the thirtieth anniversary of our wedding. It seems to me to be as fresh to me as yesterday, but I am quickly reminded of the millions of things we have in common. Sometimes I feel insecure about the
number of daily activities with which you need to help me, and then I realize that your care-giving is an expression of your love for me. We are bonded. This goes beyond any kind of marriage or social contract. It goes to the roots of our most basic behaviors, it goes to our basic biology.
We are able to finish each other's sentences, we each know what the other is thinking, we can barely remember our lives when they were separate, because of a simple protein, the hormone, oxytocin. Every time our skin came into direct contact, for the last thirty years oxytocin was released by our brains strengthening the pair bond. Oxytocin is the same hormone responsible for the 'milk let-down' reflex when a baby suckles from
its mother's breast. It is also the
hormone that is released by the brains of human beings when they reach sexual climax.
Oxytocin is the pair-bonding hormone. It is what keeps
the albatross looking for its same mate over the whole wiorld for its whole life. It is the hormone responsible for those intricate courtship rituals we have all seen

on television: pthe crane dance and the dance of the blue-footed booby. This is the year it all pays off. We'll see the results
Today from every touch we have ever exchanged in our pair-bond. Perhaps in the next thirty years
we should take up the tango?

Frank Hensley
July 2017
We are a hard-working, play-by-the-rules , middle-class, tax-paying American family. Thanks to Parkinson's disease our future inevitably points toward depending on Medicaid benefits, or becoming homeless, unemployed burdens on our extended family. Or, I guess, we could just die early.

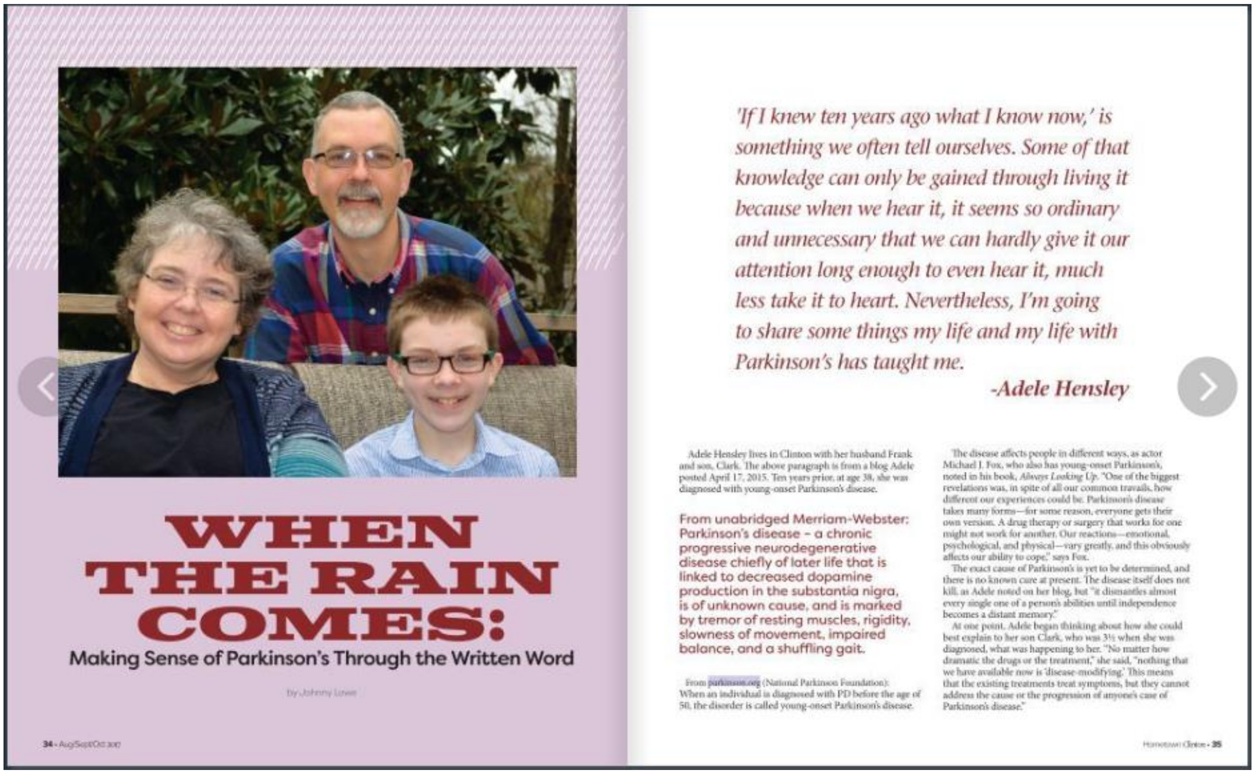
August 2017

When the fall semester of 2017 was about to begin, I knew it was no longer safe for Adele to stay home alone. We were enormously blessed that when she worked for the Presbytery of Chicago, Adele had been offered a long-term care insurance policy at a very reasonable price. Although she had already been diagnosed with Parkinson's Disease, the insurance company offered this policy with no medical questions or screening. We had paid her insurance premiums until 2011, but when she retired on disability, the Presbytery had taken over paying those premiums. So, Adele had a generous insurance benefit to draw on, and it was time to take advantage of it. Caregivers began coming daily to assist with her activities of daily living, prevent falls (not always successfully), and help with household chores. They also took her to local medical appointments, and on some occasions went with us on our marathon day trips to New Orleans to see her DBS team doctors.

Adele had published her first book, *Monica, Mama, and the Ocotillo's Leaves* in 2013. In it, she compared the effect of taking her Parkinson's medicine to the effect of rain reviving a dried-out plant in the desert. The final page reads,

> *"...My voice doesn't always sound happy, but when I have what I need, the*
> *right medicine, and a good walk, I sound, feel, and look more like myself."*
> *I see, Mama, " said Monica. "And the ocotillo will look like itself when...?"*
> *Her voice trailed off in a question.*
> *"When the rain comes again," said Mama.*

That last line was the inspiration for the title of a feature article about Adele and her books in the local Hometown magazine:



WHEN THE RAIN COMES:

Making Sense of Parkinson's Through the Written Word

by Johnny Lowe

34 • Aug/Sept/Oct 2017

'If I knew ten years ago what I know now,' is something we often tell ourselves. Some of that knowledge can only be gained through living it because when we hear it, it seems so ordinary and unnecessary that we can hardly give it our attention long enough to even hear it, much less take it to heart. Nevertheless, I'm going to share some things my life and my life with Parkinson's has taught me.

-Adele Hensley

Adele Hensley lives in Clinton with her husband Frank and son, Clark. The above paragraph is from a blog Adele posted April 17, 2015. Ten years prior, at age 38, she was diagnosed with young-onset Parkinson's disease.

From unabridged Merriam-Webster: Parkinson's disease – a chronic progressive neurodegenerative disease chiefly of later life that is linked to decreased dopamine production in the substantia nigra, is of unknown cause, and is marked by tremor of resting muscles, rigidity, slowness of movement, impaired balance, and a shuffling gait.

From parkinson.org (National Parkinson Foundation): When an individual is diagnosed with PD before the age of 50, the disorder is called young-onset Parkinson's disease.

The disease affects people in different ways, as actor Michael J. Fox, who also has young-onset Parkinson's, noted in his book, *Always Looking Up*. "One of the biggest revelations was, in spite of all our common travails, how different our experiences could be. Parkinson's disease takes many forms—for some reason, everyone gets their own version. A drug therapy or surgery that works for one might not work for another. Our reactions—emotional, psychological, and physical—vary greatly, and this obviously affects our ability to cope," says Fox.

The exact cause of Parkinson's is yet to be determined, and there is no known cure at present. The disease itself does not kill, as Adele noted on her blog, but "it dismantles almost every single one of a person's abilities until independence becomes a distant memory."

At one point, Adele began thinking about how she could best explain to her son Clark, who was 3½ when she was diagnosed, what was happening to her. "No matter how dramatic the drugs or the treatment," she said, "nothing that we have available now is 'disease-modifying.' This means that the existing treatments treat symptoms, but they cannot address the cause or the progression of anyone's case of Parkinson's disease."

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Frank Hensley to [group]

October 2017

We live by rules at our house. Here are the first six:

1. No falling.

2. No falling, dammit!

3. What the hell? NO FALLING!

4. ... I better leave the rest to your imagination.

Frank Hensley to [group]
November 2017
I'm sending strength to all of you who are trying valiantly to get ready for holiday guests or travel and colliding with PD today. Now please send some back to me? Thanks!
We have a new rule at our house: on travel day the agenda includes travel and nothing else! This morning she informed me that she needed to do an illustration for her new book before we could leave. She estimated 1-2 hours. We left home at 5:00. PM. So I had to do the entire 3-hour drive in the dark. And we only left because I insisted that we couldn't afford to wait for her to finish her art. (We'd probably still be there now!)

December 2017
Claire wrote:

"Hallelujah!" Handel's Messiah 2017

"And He shall reign forever and ever,
King of kings! and Lord of lords!
And He shall reign forever and ever,
King of kings! and Lord of lords!
Hallelujah! Hallelujah! Hallelujah! Hallelujah! Hallelujah!"

We stood shoulder to shoulder, my arm wrapped around her, holding tightly to her gait belt. "Don't fall," I warned, and she grinned before she began belting out her hallelujahs. My program was on the pew beside me and other than the chorus, I really didn't know the words. I couldn't hit the high notes, either, so I just hummed along and took in the moment. There was a lot to take in. I was amazed at my friend beside me, who had started getting ready for this moment two songs prior. She had a tight grip on the pew in front of her, and even though it was hard, she stood. And even though Parkinson's tried to steal her breaths, she sang. I'm not sure I've ever been as amazed by anyone as I was amazed by her in that instant. And oh, how incredulous I felt to get to be standing beside her. My family lined the pew in front of me, Dr. Hensley was to my left, Mrs. Adele to my right, and I silently praised the Lord for His goodness in allowing this moment to happen. What a treasure.

Edits from 2023:
When I was back at her house for her funeral, I took her phone and went through her emails, forwarding all of our correspondence to myself, because I had lost it when I graduated and MC deleted my email. I felt certain she would not begrudge my snooping through her emails for the gift of keeping her words, our conversations, forever.

On December 1, 2017, she emailed Dr. Hensley and I:

> *"I would like to go to Jackson. On December 16, my preference is to go at 3 pm but there is s7 pm performance. Amy will get me tickets but she needs to know how many. If you would like to go. Please let me know.*
> *Adele"*

I found her email to Amy, her sister, when she was coordinating getting tickets for this concert. Typing was incredibly difficult for her, nearly impossible, and much of our time together included her scribing emails/facebook posts/poems. However, she never recruited me for this email; she kept it a surprise. When I replied to her email about going to the concert together, I told her my whole family would love to go. I had no expectation that we would go for free, but she wouldn't let me think of paying. I was so touched, when I found it in 2022, to see the efforts she went to (sending a single email likely took her over an hour) to ensure my family got to see her sister's incredible performance.

> *"Dear Amy,*
>
> *I finally have a headcount for the 3 pm performance*

Of Messiah and now I feel a bit sheepish. I told Claire, who has been driving me to dance for I 2 1/2 years, so I feel like I both know and owe her,to see if her mother and sister wanted to go with us. I thought that it was pretty bold for me to ask for five comped tickets, but you would tell me if it were too many. Well, her whole family said they'd like to go. So I'm bringing eight people to your 3 pm Messiah (Frank,me and six Shraders).
I would be happy to pay for the bulk of the tickets (say six of them).just let me know if I should order online or if I need to call or what.
Also,Claire's brother,Benjamin, Is confined to a wheelchair, as am I, please ask Tippy if there are accommodations for disabled people at the church. I went to a concert at MC the other night and there were ńo accommodations and it was awkward.
Thank you, Adele"

Frank Hensley to [group]
December 2017
Called all the area theaters and found one that has a family restroom! So, we all got to see Last Jedi!

Frank Hensley to [group]
January 2018
Last night Adele felt like crap. Couldn’t move, chew food, talk, sit up straight. Sinemet and Apokyn barely helped at all. This morning was just as bad, even though she had slept pretty well (for her). On a whim she asked for her DBS remote...and it revealed that her generator was OFF! Apparently, yesterday’s mammogram did it. We turned it back on and in one minute she came ON too!

Frank Hensley to [group]
February 2018
Traveling yesterday with a colleague and students. As we were headed home one student who is a new dad commented that at least my colleague and I didn't have to go home and change diapers.... He has no idea.

February 2018
An email from Adele to Frank:

I dumped my
Pill container. E haven't found xadago and amantadine. I suspect they rolled further than we have looked. What should I do? Delly

March 2018

The Dance with Parkinson's class was a collaboration between neuroscientists at Millsaps College and the dance faculty at Belhaven University. Adele and Claire attended faithfully, but Claire had decided to do a study-abroad semester in Argentina, and she wouldn't be able to take Adele for a while. So, Claire brought Amy Caroline into Adele's life. Amy Caroline took over that role for a while, and after Claire returned from South America, the three of them expanded their activities well beyond dance.

In each class you'd likely see students majoring in dance, Parkinson's patients, family members, and faculty. You'd see able-bodied, healthy young people, seated dancers, people using walkers, and by 2018, Adele in her bright blue wheelchair. The dance students taught and encouraged the Parkinson's people, and the Parkinson's patients inspired the dance majors.

Belhaven dance majors are required to present a senior project, so of course one of them decided to bring the entire dance class into her recital. The student choregraphed all of the dancers, including Adele seated in her wheelchair, pushed by Amy Caroline. Claire and Adele recorded a voice-over for the performance, reading a poetic reflection that Adele wrote about what it means to be a dancer. The performance ended with Adele's Parkinson's-addled voice declaring, *"...it doesn't matter if you sit or walk, it only matters if you move to the music. Then you are a dancer!"*

Frank Hensley to [group]
July 2018
Tonight was the first time she ever asked me to spoon feed her.

Frank Hensley to [group]
July 2018
Adele got approved for Medicaid. They will provide caregivers, bathroom supplies, and lunch. Preliminary calculations say we will save several hundred dollars per month. Plus, now overnight care will be affordable so I can take our son to look at colleges. The only downside is we will most likely lose our current caregivers...

Frank Hensley to [group]
August 2018
Wet pants? Old news.... Dirty diapers? Yep, that's a thing now. Of course, PD has been giving us shit for 13 years.

Frank Hensley to [group]

October 2018

Forty-nine state Medicaid programs pay for pull-ups. One state considers them a luxury for those incontinent poor people that are too disabled to get to the toilet, and only pays for diapers, not pull-ups. I'd like to see the Governor of Mississippi diaper a 320 lb. person, standing or lying on a bed, so that it doesn't leak.

Frank Hensley to [group]

October 2018

For the third time, today someone assumed that Adele is my mother, not my wife. Unfortunately, this time, they did it right in front of her. I think she was probably much more upset than she let on. But damn this disease for robbing every shred of dignity from people! She's not 80 years old, she's 52!

Frank Hensley to [group]

October 2018

Trying out our new Hoyer lift tonight. Hope it lets my shoulder heal because for about a year and a half getting her into bed has been tearing me up.

Frank Hensley to [group]

October 2018

She tries to talk to the Trick-or-Treaters, but they can't understand a word she says, and the little ones are scared of her.

Frank Hensley to [group]

November 2018

I have read that caregivers sometimes, under stress, neglect self-care, including personal grooming and hygiene. For example, I'm about 3-4 weeks overdue for a haircut. I know I used to shower daily but now it's more like every 2-3 days. So yesterday I had a moment of panic when I was sitting next to my graduate student working on some data, and she said "Dr. Hensley, you smell like..." Thankfully, her next word was "soap" and not something far worse!

In 2023 Claire sent me the following reflections on dancing with Adele and taking Adele to Methodist Children's Home. These were written at the time they happened.

Dance, 2018, one of the classes Amy Caroline came to as I "trained" her for when I was in Argentina:

Mrs. Adele, Amy Caroline, and I dance off to the side when all the dancers stand, because Mrs. Adele needs to hold onto the barre, and Amy Caroline needs to be able to move the wheelchair in case she starts to fall, and I need to be able to squeeze between the wheelchair and Mrs. Adele to hold her up. It's a three-person dance, and we do it beautifully. Today, the teacher introduced a particularly hard number. I wondered how much Mrs. Adele would be able to do, until she picked her foot up, and the next thing I knew, she was standing there, two hands on the barre, one foot on the ground, the other elegantly against her ankle, my arms wrapped around her, no longer even holding her, but just wrapped in a hug. "You're amazing!" I said, smiling into her deep blue eyes. When I say her entire face shone brighter than anything you've ever seen, I mean it. She grinned deep and hard into my eyes, and then looked at herself, tilted her chin, and said, "I am!" incredulously.

Mrs. Adele and the Methodist Children's Home:

Last Monday, Chloe held the door open for us as we walked out of Bible study, and followed us into the parking lot. I've been in her shoes before: you so want to keep talking to Mrs. Adele, keep gleaning from her knowledge, keep hearing her laugh. So I asked if Chloe wanted to walk with us to the car and help us load.

My dear friend has been struggling to get into the car lately. Though we can do it just the two of us, it really helps to have one more person. So though I had originally planned for Chloe to just hold onto the back of Mrs. Adele's wheelchair and keep us company while we got into the car, she ended up doing far more. And she loved it.

We tried a couple times, Chloe holding my car door open and me holding Mrs. Adele up, until her legs buckled too far under her and I had to let her sit back down. She was frustrated, I knew, and I quietly said, “I’m sorry, Mrs. Adele, but I think you need to sit down.” Chloe grabbed her water bottle and I grabbed some pills, and I sat down in her seat in my car while she took pills and we all breathed. As we recovered, I peppered sweet Chloe with questions. She happily answered all of them, telling us her mom is in prison, where her siblings are, when her birthday is. It turned out that she and Mrs. Adele share the same birthday week, and here is where sweet Chloe said:

“Do you like cake, Adele?”

“I love cake.”

“I get checks from DHS. I can get us a birthday cake and we can celebrate on that Monday!”

These were holy moments. They were holy because Chloe got the one-on-one attention that I know she must crave. She got to be poured into by this woman who she can trust because she knows she’s walked through hard things, too. And she got to have purpose. She couldn’t stop talking about how she had cared for her grandfather, and how strong she was. She even offered a suggestion: why didn’t we just stick Mrs. Adele’s foot into the car while she was sitting in her wheelchair?

I don’t know that I’ve ever had to work so hard to stifle a laugh. “That’s such a good idea, Chloe, but for her, it’s really easier to stand up and turn around. Do you think you could help me turn her around?”

Mrs. Adele was transformed, too. The frustration she felt so palpably when we had gotten into the car and that threatened to overtake her when she sighed, “This is so easy. I should be able to do this.” as we stood waiting for her feet to unfreeze, totally disappeared as Chloe talked. Her whole face lit up as they laughed together, and then she looked into my eyes, “Are we ready to try this again?”

Chloe changed everything about that moment. It went from a moment of impossible frustration at the ways Parkinson’s slowly steals all things good and normal, and instead became a moment of pure beauty. Chloe hugged each of us once we got Mrs. Adele in the car. She apologized to her just like I had done, and said, “But it’s okay, you’re still kicking, you’re still rocking!” and made us both laugh.

She had been filled up. So had Mrs. Adele. So had I.

When I got into the car, I had barely even sat down before the joy bubbled out of Mrs. Adele: “That was so neat!” I wish my fingers could adequately convey the emotion in her voice.

It was so thick in mine I had to laugh it out, “I don’t want to say that God caused your feet to not work, but…”

“If your feet aren’t going to work, there might as well be a reason for it.” She finished my thought.

A vignette from Tuesday nights, 2018:

Tonight was my last Tuesday night of the semester with Mrs. Adele. I’ve spent practically every Tuesday with her since August. Nights of immeasurable worth. Nights of baking bread until way too late. Nights of Chinese food and chicken pot pie and subway sandwiches. Nights of getting the honor of sitting beside her and sharing a meal. Nights of getting to help Clark study. Nights of hearing of what fills his days. Nights of playing with Padfoot. Nights of ice cream once Dr. H gets home. Nights of pulling my green chair up as close to hers as I can, of pressing close and hearing her words. Nights of copying her thoughts word for word, of playing words with friends, of creating poems. Of making masterpieces. Nights of medicine and failed shot attempts and grace upon grace upon grace. Nights of Christmas tree decorating and walking practice and looking through yearbooks and remembering. Nights of handing out candy to trick or treaters and eating the good candy first and hearing Padfoot bark again and again. Nights with no agenda, nights without a schedule, nights that blend together in my memory. Nights when I left with a lighter step because being with this friend of mine fills my heart. Nights that made me wish I could spend every night like this.

I don't think words can actually sum up my semester of Tuesdays with Mrs. Adele. Memories can't even do them justice, and I certainly can't find a favorite. Though I really loved the night we looked through her old yearbooks and I read every entry out loud and then we baked challah bread until late late into the night. And Dr. Hensley fell asleep on the couch and my eyes started glazing over while I studied A&P and I think Mrs. Adele started fading, too. But the two of us became alert enough to enjoy the bread hot and fresh from the oven.

These Tuesday nights were a soft place to land during such a transitional time, a place to belong, that felt permanent even in the midst of so many changes. I walked firmly out of class each Tuesday afternoon, confident that I knew I had a place to be that night and someone to spend it with. My greatest hope is that these sweet, wonderful Tuesday nights were as great a gift to her as they were to me.

Tuesday vignette number two, also from December 2018:

I sat on their couch studying genetics for a couple of hours. Every time she needed something, she asked Dr. Hensley for it, leaving me to keep studying. And I wished I had jumped up instead. I did when they opened the bathroom door again, and got her back in her wheelchair and up to the kitchen sink.

As I pulled her back over the threshold, I asked Dr. Hensley if he had given any thought to working on the solar Christmas lights. He said he hadn't, and we all paused. I said, "Yeah, I thought you maybe hadn't…" and kind of laughed. And Mrs. Adele started laughing, and she couldn't stop. And I started laughing. And soon we were all laughing, with Dr. Hensley the last one to join. He stood there in front of her for a minute, watching, with this kind of incredulous look on his face.

There she was, ice cream dripping down her chin, words too slurred for us to understand on the first try, and a college kid who forced herself into their lives pulling her over the threshold of the kitchen. There are Christmas decorations that haven't been put up because the only ones who could are a college kid, high schooler, and professor who are in the middle of finals. And in spite of all of it, she laughed. This bubbling out of you, can't stop for anything, joyful, glorious laugh. And the way he looked at her, with admiration and adoration and this unbelieving. I know that look because it's how I look at her, too.

It was joy. That's what it was. Her laugh was the most perfect example of joy I have ever seen. Joy that defies all circumstances, all heartache, all tragedy. Joy in the face of all of it. Joy in the face of the really, really, really hard.

I wanted to write it down, because I couldn't snap a picture and I know I won't always hold the picture in my mind, but I NEED to keep the image in a place I can grasp, because I know that someday joy may seem impossible. I want Mrs. Adele's laugh to be my reminder that it can always be found.

Not a Tuesday, but rather a Thursday morning: March 28, 2019

Clark had to be at the airport at 4:30 this morning, so Dr. Hensley asked me to stay the night so I could be there with Mrs. Adele while he took Clark. So I ended all of my evenings with her this week, and they were so lovely.

Mrs. Adele and I ended up getting in bed around midnight. I slept beneath a quilt Dr. Hensley's mom made on the guest bed made until 4:00, when I woke, surprisingly chipper, and wished Clark goodbye. I felt honored to be a part of such a big day for him. As he and Dr. Hensley left, I climbed in bed with Mrs. Adele, and she greeted me with a, "Hey, Claire, how are you doing?". I wondered if we would have one of our classic 4:00am conservations, and we did. I'm telling you—the best conversations of my LIFE are at 4:00am in that room. I don't know what it is, but I understand her SO WELL and stories and thoughts just bubble up out of her head and I just revel in the listening and it is magical.

We talked about God and what faith means, and her caregiver who thinks she needs to get a recording of Dr. Hensley reading the healing scriptures out loud so she can soak them in and be healed. I laughed, then, and told her about Becca and the woman from her church who wanted to give her a bunch of "tapes." It feels good to talk about Becca out loud. To smile. Mrs. Adele has helped me process so much of that loss.

Her caregiver, Brenda, tends to talk and talk and talk and talk about healing and what Mrs. Adele has to do to receive it. She told me this morning that she feels like Brenda assumes she doesn't know anything, and that's just not true. She has studied the Bible and taught Sunday School and spent a lot of time in the church. She then told me this beautiful story. She said when Clark was a baby, she was always worried about him, and prayed things like "God please don't let anything happen to Clark. God please don't let him get sick. Etc. etc." until one day she realized: I don't have to manipulate God to take care of Clark. He's going to take care of him because He loves him. And that's the end of it. She doesn't have to beg Him to do it, because He's already got it.

I was amazed, and told her that I didn't ever do that for the people I loved, but that I should. "No you shouldn't. That's your faith and this is mine, and that's okay."

We talked about Rachel Held Evans and we talked about Clark flying alone and we talked about my running class and her concerns that Dr. Hensley has sleep apnea, until her eyes started to close and we reclined the bed again and thought about sleeping for a few minutes…until we talked about something else. We ended up just getting up around 5:40, because at that point there was no sleep to be had, haha. I apologized for being too awake to let her go back to sleep, and she laughed, "I love talking with you, Claire." And I said, "Even at 4:00am." She grinned, "DEFINITELY at 4:00am."

Mrs. Adele’s testimony (we wrote this at another 4am conversation):

“When I was 12, we moved to Germany. My dad was in the army. Before school started one day I was in my room, and I was alone. I wasn’t alone very often—there were four kids in my family—and I realized that I had not made a commitment to Jesus. Or, I actually HAD, but I couldn’t remember when I did it, so I wanted to do it at a specific time and place, so I chose my bedroom, right then.

Nobody came in and interrupted me, and I prayed for Jesus to live in my heart. I don’t remember anything else—it was very private and very personal.

The next year our family was at a Baptist retreat, and my sister Amy pursued getting baptized. She spoke with Dr. Drummond, a pastor who was at the retreat, and he counseled her concerning her baptism and a profession of faith. Amy was baptized later in the year at the chapel in McKee Barracks, where we lived. I was not baptized in Germany, and it was when I was fourteen, that my dad had to get re-baptized, and my sister and I had to get baptized, too, to join the Baptist church. Dad was born a Methodist, and at the time, you couldn’t join the Baptist church without getting baptized.

For a long time, it seemed wrong to share my testimony. I didn’t have personal time with a pastor to talk about, I just felt strange, like it was too personal to share. I was never secretive about my faith, but I was private.

Jesus has been my Lord and Savior for a long time—almost 50 years—but somehow, in my 20’s or 30’s, I became convinced that our God was not a good guy, that He played favorites, and that He would punish you for no reason. I think maybe I started believing that subconsciously after a play I was in in junior high. The play was a depiction of The Marriage Supper of the Lamb, and as Jesus (who happened to be played by my arch nemesis) headed towards the supper with a crowd of people, my character cried out, “Jesus, wait! What about me?!” I was not invited. Sometimes I wonder if I really have believed that ever since. I spent years feeling guilty about what I had done to Jesus, when he died. When we *had communion in church, I would feel guilty, and I did not trust that God was on our side.*

Recently, through this Bible study at Methodist children's home, I've become convinced that that is not true. That what He wants for His children is what is good. I came to believe that Jesus' words, "I came that you may have life, and have life more abundantly." are true.

When I first became a mother, I tried to think about a way to pray that everything would be good for my son. I tried to bargain with God, that he would be well, and that he would be healthy, and that he would be strong, and he would be smart, and he would be all the things you want for your child. And then one day I said, "No. I am not going to do this. I will pray to God that He would take care of Clark, and trust Him that He will. It's not about stipulations or tricking God/getting him to agree to something that He wouldn't necessarily do. It's about a relationship, and trusting that He will do it, and He has.

God is not waiting to punish us; He is waiting to greet us with the rich robe and sandals, at the head of the driveway, like the father in the prodigal son story.

XIII. Unrelenting Bitch

Frank Hensley to [group]
May 2019
Standing at the Walgreens counter for half an hour+ while the pharmacist talks to the insurance company. It's just as aggravating as making the call myself from my office, plus my feet hurt because there's nowhere to sit.

Frank Hensley to [group]
May 2019
Adele is losing weight. Right now that's a good thing...Requip causes compulsive eating and she's cut her Requip dose back from 12mg to 4mg and the compulsion is much reduced. She was 330+ and now she's down in the 280 range. Yep, she's lost about 50lbs! But she's not losing due to diet or exercise...she's losing due to dysphagia. She spends ALL day with a plate of food in front of her, but she gets about half her food in by me feeding her. Right now weight loss is a good thing, but what about another year of not being able to chew and swallow... where are we headed? I fear that someday her swallowing will be so bad she'll have to have a feeding tube.

Frank Hensley to [group]
June 2019
Pointless silly story with a Parkinsons twist: ...
[...I briefly told the group the Baylor Jell-O story]
Well, those of us who do not learn from history... last night I was giving her pills, as I do every evening, in spoonfuls of Jell-O. She choked and shotgunned red Jell-O all over me (glasses, iPhone, and especially my leg). She's still getting revenge on me 35 years later! We had a good laugh.

Frank Hensley to [group]

July 2019

Some days the word is drool. Some days the word is pee or poo. Today's special word is pus. There is no nasty biological substance that PD won't bring into your life. Glove up, and let's get caregiving!

Adele had so much to say about Parkinsons Disease. I had a lot to say, too. And Adele and I did our best to shield Clark from the worst of Parkinson’s. But Clark is smart and perceptive, and he lived his whole childhood under the shadow of Parkinson’s. He eventually followed his mother’s lead and put his thoughts into words. We don’t actually know when he first wrote this, probably some time prior to the summer of 2019, but it belongs here:

The Monster

It must have snuck up on us, but if it did, then why does it feel like it was always here? It was good at first. I think it was good, anyway. I didn’t understand it then. I’d be lying if I said I understood it now. It was good at first. It put a name to the unknown, the looming threat. Slowly we met the devil-we-didn’t, and thus the relief of knowing its true name was crushed under the terror that was its true face.

It changes quickly, but it only creeps forward. Does it really creep? I’m not sure anymore. I wasn’t ever sure. I can’t tell if it crawls ever onward at a determined snail’s pace, or if it leaps forth and then slumbers, a twisted hare in an eternal race against the tortoise that is us. Can this tortoise do it? Can we beat it? Do we bother trying?

We can try to fight it. We use machines, chemicals, other sorts of modern weapons. Some people pray about it. Does any of it help? Maybe, at least for a little while. It hinders it. Or maybe we’re just distracted from it. Then it evolves again. It changes tactics. It mutates. It is the perfect virus. If only there was a vaccine.

Here I am, free of its clutches, but at what cost? If I am not there, will they be okay? What if it gets bad? What if it gets good? How will I know? How can I tell the difference if it’s all I’ve ever known? In some ways, I was never in its clutches:

I just watched as its claws tightened on them. In other ways, I suppose it still has me.

Lots of monsters are slain by great heroes. A gallant knight wielding a battleaxe rides into the scene, calls upon his god, and smites the evil. If that's what's supposed to happen here, the knight-errant must have gone off-course. Some monsters aren't beaten by feats of strength. They have to be studied, understood, avoided, tricked, or any other number of more clever solutions than "strong man rides in and commits violence." I assume that that must be the kind of monster it is, but I haven't found the clever solution yet.

So there we stand. We try to stay ahead of it, though I fear that it's sprinting ahead of us. I look back sometimes. Was it ever better? Has it always been like this? It's felt dire for so long that I don't know if I should worry anymore.

Frank Hensley to [group]

October 2019

Got her in bed at 2:21 AM. This routine is killing me.

Frank Hensley to [group]

October 2019

At the urologist the nurse looked at me and said, "Is that your mother?"

No, dammit! That's my wife!

It's the third[21] *time someone has made that mistake, the first time being almost 10 years ago. But this was the first time Adele heard it. She didn't say anything until hours later, and even then she was pretty matter-of-fact about it. But I know it hurt her feelings.*

Frank Hensley to [group]

December 2019

We are ok. But I dropped her yesterday. I was trying to help her get into our van, and we had a chance to be on time to church if we rushed...so I was in a hurry. I grabbed her gait belt and on the count of 3 we started to stand up. But I forgot

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[21] Actually, the fourth, but sleep-deprived caregiving spouses can't keep track of everything.

to check if her feet were well positioned. And I didn't just drop her. I went down with her, and we took the wheelchair over with us. We landed on the wooden wheelchair ramp, but I controlled our fall so neither of us hit our heads. Scary, but no harm done except my always-tender shoulder is worse today. Why do I have to keep re-learning to be patient? So y'all remember to be careful and patient today, OK?

Frank Hensley to [group]
December 2019
Changing a baby's diaper is just routine work - we don't think of it as a horrible thing for the baby. In fact, I think lots of little kids like the focused attention. But changing an adult's diaper is such a dehumanizing indignity for them. To be so helpless, so dependent, so vulnerable, so needy, so incapable of self-care. I hate it for her. And I hate that she has to have help from people who don't even know her - they can't see her as a person in that situation...just as a dirty diaper.

Frank Hensley to [group]
January 2020
Urgent call to come home. She fell while her caregiver was helping her dress. Fortunately, she seems fine and the cut behind her ear doesn't look like it has to be stitched. So now I'm back at the office, but I've lost all momentum for the day.

March 2020

When the COVID-19 pandemic hit, I was very concerned that if Adele caught it, she'd be at very high risk of complications. We tried our best to avoid it, but eventually we both got sick. When she tested positive, I took her to the hospital for an antibody infusion, which at that time were only available to high-risk patients. She wasn't quite old enough to qualify, and Parkinson's wasn't on the list of qualifying conditions. She had been losing weight due to difficulty chewing and swallowing food, and the emergency department had no way to determine her actual weight. The doctor in charge was skeptical that she was heavy enough to qualify for the infusion, but I assured him she was, so he approved the treatment. We will never know how much that infusion affected the course of her COVID-19 infection, but she ended up with a mild case.

In retrospect, Adele probably wasn't heavy enough to qualify. She had begun a long, steady weight loss that her neurology team in New Orleans celebrated but would eventually turn against her. Nobody knew it, but Adele's increasing difficulty with chewing and swallowing was beginning to starve her.

Frank Hensley to [group]
August 2020
Caregiver Pro Tip: If you don't want to end the evening with a sink full of dirty dishes, try leaving them scattered all over the house. You're welcome.

Frank Hensley to [group]
September 2020
Except for nights when I was in charge of students on class field trips or my own son on college visits, I have not had a night free of caregiver responsibilities since January of 2013[22]*. I'd give a month's salary to go camping alone for 3 days.*

Frank Hensley to [group]
January 2021
Ok I need your ideas. I tested + for COVID-19 this morning. Adele has not been tested but she's certainly been exposed. I've always assumed she'd be the one to get sickest. But what if I have to be hospitalized? What would happen to her? I assume if an ambulance came to get me, they'd call a social service agency to try to find a place that could take her in. But if she's sick or tests + how would that work?

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[22] This statement was not factually true, because I'd had a few nights at home when Adele was hospitalized, but my feelings were genuine even if my memory was confounded.

Frank Hensley to [group]

January 2021

The caregiver dropped her, and she hit her head on the floor. She's fine. No concussion. No bruises. But God I hate this disease!

Frank Hensley to [group]

February 2021

She's too trusting and no longer capable... she gave her caregiver full access to her bank account. I asked her how much money she had given her caregiver and how many times. She said $100 x 2. But there have been four transactions in the last 6 weeks for a total of $500. I'm not saying she didn't authorize it, but she doesn't remember. So, I changed her bank account password to something only I know, and I blocked the caregiver on CashApp. I will explain to the caregiver that no more money changes hands without my permission.

Frank Hensley to [group]

March 2021

I miss her the most when I'm with her.

Frank Hensley to Claire

March 31, 2021

Claire, I'm sorry you were frustrated by last night's call with Adele and her lack of communication. One big factor was that Denise thought Sherrie had given Adele pills and set a timer before leaving, but that was not the case. So, Adele was more than two hours overdue for pills for much of that call.

Unfortunately, Adele's communication does not correlate clearly with her medication timing. We are at the dentist right now and Adele is due for pills in about 20 minutes but her ability to talk to her hygienist is much better than it was 20 minutes ago. Why? Who knows?

So, the bottom line is that last night could have been better but there's no guarantee. Regardless of when we schedule a call, Adele can be at her best or her

worst. Time of day and food and pills interact in such complex ways that I can't figure out a perfect time to call.
As for a painting activity, I have mixed feelings. Adele seems to have given up any aspirations to paint for her butterfly book. She's frustrated that she just can't do what she used to. I can't tell if trying to paint (even with a fun kit) will only frustrate her more and put salt in that wound, or if doing something with you online will be a HIGH for her week. I just don't know.
Perhaps we should find a way to play a game together. Maybe something that is an electronic form of a traditional card game or such, like UNO, where there's luck involved but not much in the way of skill. I think she has completely quit Scrabble and Words with Friends because she just can't manipulate her phone or iPad. It's the progressive nature of the disease that she's losing abilities. I hate it for her. I don't want to withhold something fun, nor do I want to push something frustrating. But maybe a card game that's based on the hand you're dealt and doesn't require fast typing or screen work might be the way to go. We could do something in teams and maybe even with screen sharing we could mix teams up so Adele doesn't have to have me as a partner all the time.
That's my best idea.

Frank Hensley to [group]
April 2021
It's the kind of morning where I can't find my wallet because it is floating in the toilet.

Frank Hensley to [group]
June 2021
Do y'all notice little milestones on the journey downhill? Today is the first day I ever brushed her teeth for her. She was brushing with such slow, short, pathetic strokes I couldn't see how it was doing any good. So, I asked if she wanted help. Mostly she has relied on an electric toothbrush for years, but hers broke a couple of weeks ago. Only today did I notice how badly she was brushing. I'll get her a new electric, but it's just one more thing she can't do on her own anymore.

Frank Hensley to [group]

October 2021

2:30 PM and I have to quit writing tomorrow's exam to take her to a dentist appointment. But no big deal...dentist, pick up a quick dinner when we are done, head home, and get back to work on the exam.

4.5 hours later I'm finally at the computer. I hate Parkinsons.

Frank Hensley to [group]

November 2021

Anticipating a small win...I'm extremely grateful that Adele has caregivers. They keep her safe and clean and dressed and fed and entertained and I couldn't do my job or get out of the house without them. But one of them drives me absolutely crazy. Like, she's the biggest source of stress in my life. But I think I found someone to replace her! Fingers crossed!

Frank Hensley to [group]

December 2021

*PWP is fully dependent on help with bathroom activities. So explosive diarrhea has to happen the week the clothes dryer dies and it's way too humid for a clothesline to work. A perfect sh*tstorm. The new dryer will be delivered tomorrow and it's the best Christmas present ever. But how many times will I have to change her clothes before it finally arrives?*

Frank Hensley to [group]

December 2021

How her PD plays with MY brain. I'm a birder so I keep up with local sightings, etc. I "met" a local guy on the internet who invited me to go birding with him. I explained that I almost never get out except with my students, as part of my job, due to my wife's PD. He says, "What a coincidence... MY wife has PD, too." So, I think wow! A new friend I have TWO things in common with. Then he tells me he has AFIB and can't take care of his wife anymore, so she lives 100 miles away with their daughter. And I actually was JEALOUS of his poor health! He didn't have to lose his wife to PD to be relieved of the enormous burden of caregiving.

And then I thought about what I was feeling and now I feel really guilty that I'm jealous of him. I hate PD and PD hates me!

Frank Hensley to [group]
March 2022
Adele takes pills every two hours. She's trying to swallow the 6th pill of this round. There's 9 minutes left before her pill alarm goes off again.

Frank Hensley to [group]
March 2022
This morning I specifically asked the substitute caregiver to fold a load of laundry. She didn't. Nor did she wash a single dish all day. Nor gather up wet towels and pajamas after Adele's shower and start the washer. But the agency struggles to find substitutes, so I really hate to complain. She's holding the aces. <sigh>

Frank Hensley to [group]
April 2022
At 2:30 this morning Adele was finally ready to go to bed, so I was transferring her between wheelchairs. But I had been sound asleep just minutes before and my brain was fogged, so I failed to use good technique. I didn't place my feet properly nor transfer my weight properly, and I started to drop her. I used all my strength to shift and lift and managed to get her in her wheelchair safely, but this morning every muscle in my back and legs is screaming at me. I probably need to quit doing manual transfers and just use her electric lift every time. I make all her caregivers use it, but I have been in too big of hurry to make myself go get it. Now I'm paying the price. I'm just glad I didn't drop her. Two nights ago, her caregiver let her fall off the toilet at midnight. She wasn't hurt. But she's just getting more prone to falling all the time. Two more weeks of the semester and then things get easier.

Frank Hensley to [group]

June 2022

Had to fire our long-serving caregiver yesterday. She was turning in fraudulent shift information - not coming to work but telling the agency she was here. She asked me to lie for her and say she worked when she didn't. She's been with us for 5 ½ years. Because this was Medicaid care, it didn't cost me any $ out of pocket, but it does mean that while she was getting paid, I was doing the actual work she got paid for.

Fortunately, the agency found me a very hard working and competent substitute last week, and I've made her our new permanent caregiver.

Frank Hensley to [group]

June 2022

I need my wife. My family has experienced a horrible tragedy. The kind of thing where you rush into your spouse's arms and sob, and they hold you tight and say words of comfort. But she can't provide that, because of Parkinsons. She loves me so much and she would do anything to ease my pain. But she can't hug me, and I can barely understand a word she says. She's right here, but she can't be here for me when I need her. God, I hate this disease.

Frank Hensley to [group]

August 2022

So last week Adele had a colonoscopy. She'd had a couple suspicious polyps removed before, so they wanted her back in 5 years. At that first procedure a traditional prep didn't work very well. So, this time we decided to try a new option called Hygeia that basically uses a gentle stream of warm water to flush the colon out. After 2.5 hours, the tech declared her ready for the scope. So, the next day we went in, and the GI doc said he saw absolutely nothing wrong with her...as far as he could see. Only the lower half of her system was cleaned out. So, mixed results. But we were relieved there was no obvious problem.

The doc said, however, that he thinks the prep and procedure are just too stressful to ever bother to do it again. I was kind of shocked at this. About 30 years ago my grandmother was deep in dementia, lingering in a nursing home. When she was diagnosed with breast cancer my mother and my aunt agreed *that they would not treat it and hoped it would help accelerate a merciful end because she had no quality of life. Well, that's exactly what I felt the GI doc was saying about Adele...if she has or gets colon cancer it isn't worth finding out. He was judging her quality of life from just encountering her in pre-op. I am sometimes shocked at how people perceive her (assuming she can't understand them because she can't speak, or assuming she's my mother not my wife, based on a superficial look). Anyway, this was just another case of me realizing how other people, including medical professionals, see her.*

Warning: I'm about to get pretty negative...you might want to stop here if you are trying to maintain a positive, hopeful outlook.

This kind of thing gets me thinking about how hard and grim the future might be. About a year ago I was reading on a FB group that deals with religious faith and whether it helps or not. One commentator was talking about her loss of faith in the process of caring for her elderly mother who had Parkinson's. She described the huge frustration she felt as her faith community kept offering false hope and how that eroded her faith. Her final statement was "My mother died a horrible death." I'm haunted by that phrase.

Sorry to unload on y'all. Thanks for caring!

September 2022

I thought we had more time. I thought she'd hang on for several more years. Adele no longer did anything but eat, sleep, and watch TV. There was no way she could ride her trike. There was no dance class. Her efforts to write and illustrate another book had spiraled into frustration. Claire had tried so hard to help her produce a children's book about monarch butterflies, but Adele couldn't do any art without ruining each attempt with stray marks, spilled paint, smears and smudges. Adele's joy in life came from cheering for Clark's accomplishments in college, and from celebrating Claire's progress through Occupational Therapy school. She was happy, but the grind of Parkinson's disease was relentless. She had progressed to very high doses of medication, and with that came lots of unpleasant side effects. Her DBS was still helping her with the worst symptoms, but as her condition advanced, changes in programming of her DBS had little effect.

Frank Hensley to [group]

September 12, 2022

A few years ago (4?) Adele's Dr. was really happy that Adele was losing weight. But she wasn't trying to lose weight and after 3-4 visits where Dr. was really happy, I pointed out that it was due to eating difficulties. But the weight loss was still in a healthy direction. 4-5 years ago she was 320+lbs. A couple of months ago we were at the pulmonology clinic, and they wanted an updated weight, so we stood her on the scale and helped her balance. That's not very accurate...but it was 199. I was kind of shocked. I started wondering how fast she's losing, so I bought a scale for the Hoyer lift (which should be much more accurate than standing her up). Used it tonight for the first time...188. I'm going to track this, but if she's losing 5lbs per month in another year she'll be in trouble, and we will be thinking about a feeding tube. I'm kind of vague on the different kinds, but the risk of infection troubles me... I hate Parkinson's.

In September, she developed a pressure sore. Since she spent all of her time either sitting in her wheelchair or lying in bed, there was no relief from the pressure. Her slow, steady weight loss wasn't due to better nutrition or eating habits; she was losing because eating and swallowing were getting harder. From 2021 she lost over 100 lbs. I began to worry that her weight loss was a portent of serious problems, but I didn't know just how it would go. Folds of loose skin get pinched, and pinched skin doesn't have good circulation, and pressure sores can occur. Once the skin is broken, proper wound care is essential. In early 2022 Adele had recovered from a pressure sore, but in September it recurred, and this time infection set in. Her primary care provider ordered home health nursing, and they began visiting every other day to monitor the sore and clean and bandage it. But in the last week of September things took a rapid turn for the worse.

Frank Hensley to [group]

September 27, 2022

Another sucky day...another sucky milestone. I bathe Adele on Sundays only...the rest of the week her caregivers do it. So, on Sunday I noticed that her pressure sores were worse, after they had been gradually healing for a few weeks. Last evening I had her caregiver call me to look, and I immediately set a reminder to call the home health nurse this morning. But before I called the nurse, she called me to say that she was coming to catheterize Adele on the PA's order, based on Friday's examination of the sores. So now Adele is catheterized and supposed to mostly stay in bed, rotating from side to side, with minimal time on her back or in her wheelchair.

I'm thinking back to other major milestone days. The last time she ever walked (from bed to bathroom; scared me how dangerous it was). The last time she ever spoke a clear sentence in her normal voice (which I hadn't heard for weeks and then suddenly one perfect sentence came out; never again). So, was yesterday the last day of her life she's spent out of bed? It seems likely.

*This F$%^&*g disease is a relentless b*&^%.*

Early in the week, Adele was prescribed an antibiotic, but the pharmacy couldn't get it until Wednesday. I think it was already too little, too late. I'm sure that if she'd had a fever on Monday, the nurse would have been more concerned, and perhaps taken steps to have her hospitalized for intravenous antibiotics. But her temperature was normal, so routine wound care and oral antibiotics were the plan.

On Friday morning Adele was lethargic, but I detected no fever, and I knew it would take a couple of days for the oral antibiotics to really turn things around. Adele's regular Friday caregiver was unavailable, so a substitute came. About 10:00 the caregiver called me to ask me to come check on Adele, so I zipped home. She was still lethargic, and I knew she felt bad, but I wasn't very worried about her. When I helped her roll to her side to take pressure off the sore, she whimpered a little and said "Hurts." I asked if the rolling hurt or just the bedsore, and she said it was the sore, so I told her I would leave her on her side if that was best. She nodded. I kissed her, told her I loved her, and went to teach my next class.

When my research time with my students ended that afternoon, I headed to the grocery store. While I was there the caregiver called again to say that Adele was not responding to her. I told her I'd be right there, but my worry only increased a little bit. When I arrived home, the substitute was gone and Adele's regular evening caregiver, Sharon, had just arrived. We immediately confirmed that Adele was unresponsive. I asked Sharon to call 911. It was about 4:30 PM.

I assumed the paramedics would transport her, the hospital would give her intravenous antibiotics, and she'd be okay. But shortly after the paramedics arrived, the one in charge asked me what interventions I wanted. That's when the seriousness of the situation hit me. Adele's oxygen saturation was around 50 percent, and probably had been for quite some time. Her body was still hanging on, but really, her battle with Parkinson's was over. I called Clark, Adele's parents, and my sister and Kurt. Then I climbed into our bed and held her and told her once again how very much I loved her, and I thanked her for all that she had given me. She slipped away about 5:30. In just about an hour I went from somewhat worried, to amputated and alone.

Frank Hensley to [group]
October 1, 2022
Some of you saw my post on my own page, but I should let the whole group know that I lost my sweet Adele last night. I'll say more about that here in the coming days, sharing stuff with you that I won't share with others. For now, though, please keep our family in your thoughts and prayers.

*****

Adele's Obituary:

Adele Pfrimmer Hensley departed this life Friday, September 30 after a lengthy battle against Parkinson's Disease. Adele was a proud mama, singer, educator, scientist, professor, poet, author, storyteller, cyclist, voracious reader, artist, and illustrator. When she was diagnosed with Young-onset Parkinson's Disease she discovered a lack of books for children of YOPD parents. She filled that gap with books for kids about diagnosis, brain surgery, and facing fear. Her battle against Parkinsons became her muse for a volume of poetry about living with the daily challenges. In addition to her artistic endeavors, she got

violent with Parkinson’s, earning her Black Belt in Taekwondo. And when Parkinson’s got the upper hand, she courageously faced two brain surgeries to fight back.
Hensley earned her bachelor’s degree from Baylor University, where she won membership in the prestigious academic society Phi Beta Kappa, and where she published a scientific paper about bats. She earned a master’s degree at the University of Florida with a thesis on environmental estrogens. She was awarded a Claire Boothe Luce Fellowship at Duke University where she pursued a PhD in Zoology until the early stages of Parkinsons set in. She pursued dual careers teaching music to children and doing science education for all ages. She taught music at the Duke School for Children, as an employee and volunteer at Methodist and Presbyterian churches, and with Music Together in Phoenix. As a science instructor she taught college-level biology, botany, and physiology, but also worked as an educator for the North Carolina Museum of Natural Sciences, the Arizona Game and Fish Department and the Phoenix Zoo. When Parkinsons took so much of her voice that she could no longer teach, she applied her education background at the Presbytery of Chicago where she served as the librarian to more than one hundred churches.

She was a member of First United Methodist Church of Clinton, and Parkinson’s Dance of Jackson. She was a regular volunteer at the Methodist Children’s Home until Parkinson’s and a pandemic took that from her. Parkinson’s Disease took many things from Adele, but it could not take her determination, fight, and spirit. She was also a great friend who loved to sing, bake, laugh, play in trombone choirs, and who had a ready smile for everyone. If you knew her before Parkinsons took hold, you would know her powerful alto singing voice and her unbridled laugh that filled any size room.

Adele is survived by her loving and devoted husband Frank Hensley and wonderful son Clark Hensley, parents Robert and Faith Pfrimmer, sisters Amy Pfrimmer (Gregory Miller) and Anne Pfrimmer, brother Andy Pfrimmer, and in-laws Roy and Nancy Hensley, and Celest Hensley Puls (Ken Puls).

In lieu of flowers, the family requests memorial gifts be sent either to the Neuroscience Innovation Fund at Ochsner Health, to the Methodist Children's Home, 805 North Flag Chapel Road, Jackson, MS 39209, or the environmental conservation fund of your choice.
Funeral services will be held Saturday October 8 at 1:00 PM at First United Methodist Church in Clinton, in the Connections Worship Center. Visitation with the family will be at the same location at 11:30 AM.

* * *

Right after Adele passed away, Clark told me that he couldn't remember what her voice sounded like when he was a small child. I was sure I had long ago lost all recordings of her singing, but I went looking and found some old cassette tapes of Night Air. Adele's final performance was at her funeral, where we played a recording of her singing *Auld Lang Syne* with Night Air. You can listen to her sing a few Night Air songs, including some solo and duet work, on her YouTube channel.

October 2022

Two days after Adele passed, Claire sent me this undated excerpt from her personal journal:

"She is still teaching, only instead of biology, she teaches how to find joy and purpose and resilience in the midst of an impossible diagnosis. She is still singing, only the words are printed in her poetry book, not belted from the choir loft. Mrs. Adele is passionate not just about making a difference in the world, but she is passionate about community. She is passionate about bringing people together, and reminding them they're not alone, something she has learned too much about."

Five minutes of pain - October 2022

My dad told me once that this life is like five really hard minutes. But in comparison to eternity, that’s all it is. Just five minutes. Sometimes those moments are unbearably hard. But you can do anything for five minutes right?! Then it’s eternity.

One night that was particularly difficult, I told Mrs. Adele that. It got us through. Some time later, she was crying I remember, and she said to herself, “it’s just five minutes.”

So much of her life was so impossibly hard. She faced it bravely every single day, with her own spiritual wisdom and a lot of grace and patience and faith. But so much of the end of her life looked like that: surviving. I think she was exhausted. Her five minutes were up.

And she deserves to be in the presence of God, fully able to stand and sing “It Is Well”. Just a couple months into knowing her, we went to a concert together where she sang that song. I remember it was the first time we had gone anywhere other than dance class. Our friend from dance (who was also a friend of my relatives, as it turned out) was singing in a concert. When I asked her to go, she initially said no; fearing that her symptoms at night would be too much for the two of us to handle alone. But then she texted back: “Frank thinks we can handle it.” And we did (As a favorite quote of hers says: “The weight of the world can be borne by all of us, though it would crush each of us.”). She stood up along with the congregation and sang “It Is Well”, and I was amazed. It was hard, she fought to stand, her voice was soft, but her faith was so strong.

Now I know her voice is loud and strong, the beauty of it stealing the breath of others, rather than Parkinson’s stealing her own. She can stand without doing the stand/pivot dance. She has earned her eternal rest, her precious reward for her faithful efforts to shine her light upon this dark world. She deserves the largest crown.

I tell myself, as I reflect, that she was ready. But I was not and am not ready to say goodbye to her. I don’t know how I’ll do it tomorrow. All I can do is pray for Him to give me a fraction of the strength He gave her. And if she taught me anything, it’s the fact that tears that steal your words can and should be shared and that’s ok too. Oh how much I love her. As my plane touches down in Jackson, I acknowledge that my five minutes of pain still have a long way to go, and I just wish she was here. I wish I was going to hug her and tuck her into bed tonight.

XIV. After Delly

February 2023

My first birthday without Adele was looming. For my birthday she used to cook whatever I asked for and bake me a cake. Often from scratch. Eventually Parkinson's Disease stole her ability to cook, and we transitioned to restaurant food and even brownie mix. But now I was faced with a birthday all alone… but this lonely journey was no step into the abyss. I had been shoved.

Over the years whenever my students would mention their engagements or wedding plans, I'd offer up our snail collecting story as an example of how you know you're right for each other. Shared interests, shared adventures, and shared downpours. My former student Claire, who spent so many hours taking Adele to Parkinson's Dance class, probably heard the story several times. So, she secretly reached out to another former student, Miranda, who is a potter. The plotter and the potter came up with a design, and on Saturday before my birthday, Miranda delivered her masterpiece mug. In addition to portraying us, Adele in her dress and me with a snail bucket, Miranda surrounded us with raindrops. The rest of the mug is covered with large raindrops, various snail shells, and a perky snail perched atop the handle.

I struggled to keep my composure when Miranda gave it to me. Raindrops may have been motionless in clay, but they were sure moving in my eyes as I realized how much went into getting the story baked into the clay the way it is baked into me.

July 2023

A coda to this story from back in February. My colleague from Chicago, Mark, a Music professor, came to visit. I gave him a bunch of Adele's musical legacy to take back to Chicago and share with his students. He took rhythm instruments, music books, and her trombone. When we opened the inner compartment of her trombone case, we found her drill sheets for the Homecoming halftime show on November 8, 1986. So now I know the exact date she pledged her love to me by picking snails off the road in the rain! Claire and Miranda, your plot to surprise me now has another beautiful surprise ending. Thank you both, again, so very much!

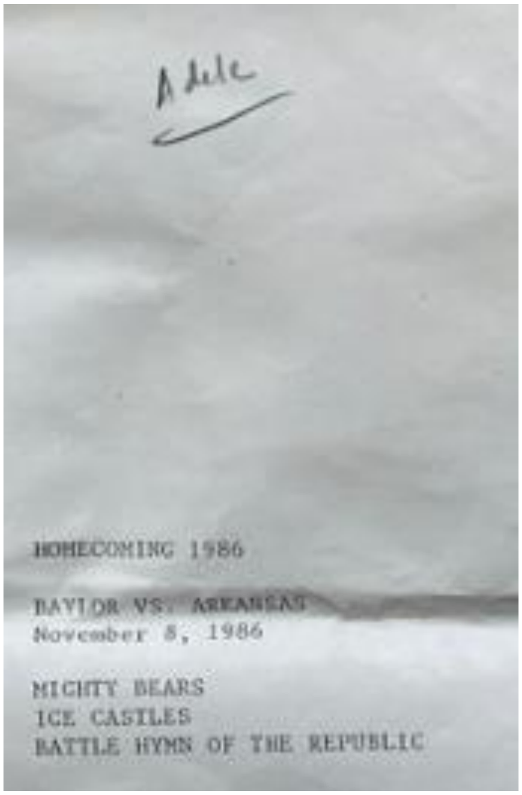
BAYLOR UNIVERSITY
GOLDEN WAVE BAND

Adele

HOMECOMING 1986

BAYLOR VS. ARKANSAS
November 8, 1986

MIGHTY BEARS
ICE CASTLES
BATTLE HYMN OF THE REPUBLIC



Adele

HOMECOMING 1986

BAYLOR VS. ARKANSAS
November 8, 1986

MIGHTY BEARS
ICE CASTLES
BATTLE HYMN OF THE REPUBLIC

At Baylor when I visited Adele's apartment, her roommate Sharon would point out that the clutter around the place was Adele's fault. She warned me that Adele was a disorganized packrat. I assumed that once we were married, Adele would keep our future home much cleaner and more organized…after all, she was in love with me, not with Sharon! And for 36 years I lived among Adele's growing accumulation of disorganized stuff. But today there are treasures among the trash. Memories among the memorabilia. Tokens of love in trombone cases.

And now, November 8th will always be the first day to celebrate after September 30th brings its annual reminder of loss. Anniversaries can be bitter or sweet. Rain can drown or replenish.

July 2023 from Claire to Frank

Wanted to share something from tonight with you…

Tonight I had dinner with a friend of mine whose mom has PD (long ago I gifted her Mrs. Adele's books that y'all mailed to me so I didn't have to give up my precious copies). My friend shared that she's been struggling ever since her mom shared that she feels abandoned by God. And now communication has gotten too difficult for them to really discuss her faith so my friend is left wondering how her mom is feeling about it all now.

Of course I don't know her mom well, so I could not really say, but what I could and did say was that when Mrs. Adele and I first met, she sent me her poems and I "copy edited" them. Along with the edits I wrote up little comments for each poem, and though I don't remember exactly what I said, I remember being heartbroken to read of her loneliness in some of those poems and wrote to say I wished I could do something to help.

In response she emailed me this:

“Dear Claire, thank you for the for these comments. They are very helpful to me.
Every poem Was a moment
in time. *So although they show how I was feeling, they don't necessarily show how I feel.* Thank you for giving them your time and your good intellect and your kind heart.”

That line in asterisks is the one I shared with my friend; the hope that though her mom once felt that way she may not feel that way now. I had forgotten the rest of her email and it was a gift to find the rest as I composed this message to you (though it made me cry again; I am a baby). She was infinitely good to me!

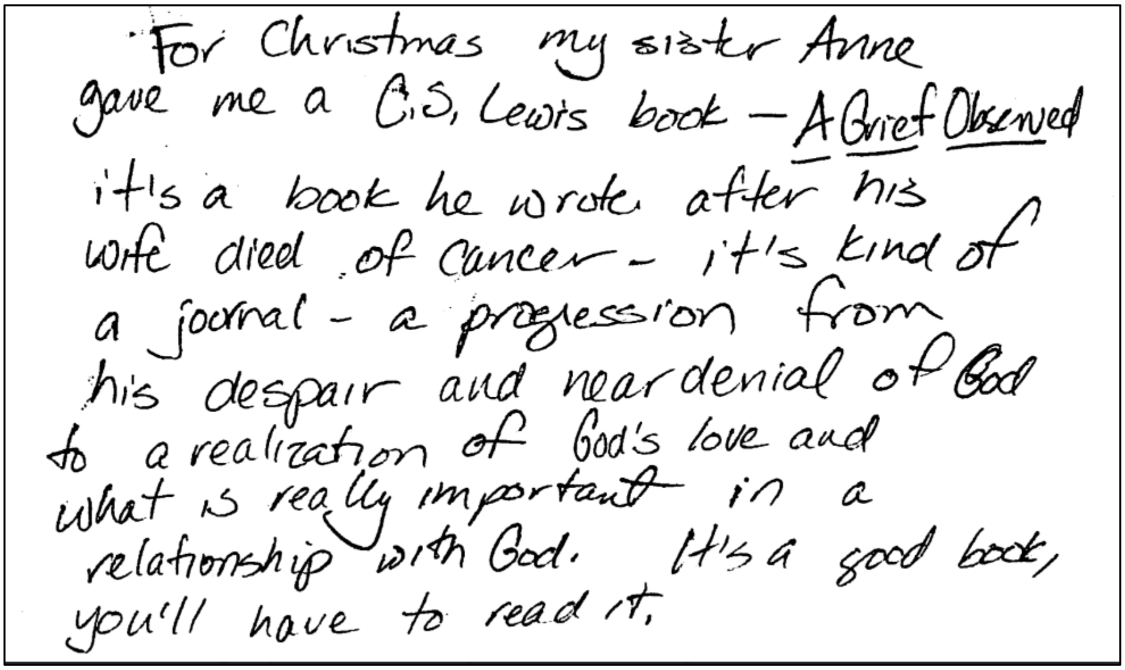
Anyway, it was a rare sacred moment to get to share her words which continue giving people hope. I definitely would have told her about it so wanted to share with you. Thanks for always humoring me 😊.

Epilogue: Will the Sun Come Out?

As I write this, it has been eleven months since I lost her. The eleven longest, loneliest months in human history. The anniversary of her departure looms on my horizon. I've made it through Thanksgiving, Christmas, birthdays, Valentines Day, and our wedding anniversary. But September is on my doorstep, and it seems daunting. Going through her writings and her art has been comforting, but I'm still feeling amputated.

I know what she would tell me to do, because she told me, almost 40 years ago:

January 2, 1985



For Christmas my sister Anne
gave me a C.S. Lewis book — <u>A Grief Observed</u>
it's a book he wrote after his
wife died of cancer - it's kind of
a journal - a progression from
his despair and near denial of God
to a realization of God's love and
what is really important in a
relationship with God. It's a good book,
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For Christmas my sister Anne gave me a C.S. Lewis book – <u>A Grief Observed</u> it's a book he wrote after his wife died of cancer – it's kind of a journal – a progression from his despair and near denial of God to a realization of God's love and what is really important in a relationship with God. It's a good book, you'll have to read it.

How fitting that my first overture to her was our shared interest in a C.S. Lewis book, and now at the end, I find another reminder that circles me back to that beginning. Back then, C.S. Lewis was a focus of intellectual curiosity and spiritual hunger. But to be honest, I also read Mere Christianity because it was a thing you did to show others (girls) you were smart and serious about your Christian faith.

I gave away her C.S. Lewis books this summer. A couple were gifted to specific people, for specific reasons. A Grief Observed and Mere Christianity went, too. I've never read A Grief Observed. And now, I can't bring myself to do it. It seems like it would bring closure.

Closure I don't want.
Closure I can't stand.
I don't want closure. I want Adele.
Oh, how dearly I want Adele.

Acknowledgements

So many people should be named in this story but are not. Dear friends and family who meant the world to Adele, who were a huge part of her life and shaped who she was, are not mentioned. Adele was so deeply connected to so many people that it would take hundreds more pages to properly tell their part in Adele's story. And even if I tried to list you all here, I'd inadvertently leave someone special out. Many of you are mentioned in the hundreds of pages of her journals that she wrote in the mid 1990's, but some of you came into her life after she could no longer leave me words about you. For this reason, I'll never know the depth of your contribution. But please know this: if you loved Adele then she loved you, and you made her who she was, and for that I am forever grateful.