



**My Nerves Are Bad:**

***Experiences from Beyond the Scars***

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### **Abstract**

This project is meant to call attention to the disadvantages that may not be readily obvious to those who have never experienced disability. Using an online mixture of narrative, sound, video, and imagery, I wish to engage and disorient an audience in a thought-provoking and feeling-inducing experience to elicit an approximation of empathy.

<http://michellerudolph.com/finalproject>

**Afterword**  
**My Nerves Are Bad: *Experiences from Beyond the Scars***

**Background**

October 2013. I am 5,000 miles from home, taking in the art and architecture of the remnants of the former Soviet Union. Neither my husband nor I speak Russian or read Cyrillic, but with city guide in hand, we are game to take ourselves on a tour of Moscow. Given that the city is a sprawling megalopolis with the worst rated traffic in the world, we rely on the Moscow Metro for transportation.

I have ridden the subways in Paris, London, New York, and Berlin, but using Moscow's sparks an unusual connection for me. The process of navigating the stations is the same as any other; the only major difference is that Moscow, still recovering from its communist past, is not equipped for tourists. Once inside the Metro turnstile, you see nary a Latin character. The posted signs are probably analogous to those you would see in other public transportation networks, but to those of us unfamiliar with the Cyrillic alphabet and with zero understanding of spoken Russian, it seems quite a feat that we are able to travel to our destinations successfully. We can see the signs; we just can't read them. We can hear the announcements over the loudspeakers; we just can't understand them.

The simple act of riding a subway is disorienting in itself. Because the trains travel through an underground maze of tunnels, there are no landmarks to guide you. Looking out the windows between stations, you see only darkness.

The unfamiliar-yet-familiar environment causes me to reflect on the six-month-long period of acute vision impairment I had experienced more than two years prior to our trip to

Eastern Europe. At that time, too, I had been able to see but not read. Everyday tasks were familiar, yet confusing. I relied on habit and memory, and when I could go no further on my own, I had to learn to ask for help.

That reflection resulted in this project.

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How does a person who's been through—or lives with—an inexplicable and untranslatable experience communicate the meaning of that experience in a way that conveys adequately the confusion of an incomprehensible condition? Mere words seem not to suffice.

Rather than a written account, I chose to create an immersive multimedia environment to emphasize the profound experience of sensory loss, through sensory manipulation. My goal? Tell a story in such a way that a “perceptual dialogue” evolves where the “viewer actively participates in the construction of meaning” (Pepperell 395). Both figuratively and literally, my intention is to generate an awareness “either painfully or enjoyably—of the active, subjective nature of seeing” (Pepperell 395). By interacting with the subjective vision I have created, there is ample opportunity for transference. Because this project is interdependent, the user is positioned as “performer of the narrative,” and each then “contributes [his/her] own idiosyncratic inflections and absorbs the experience into [his/her] own personal archive of memories” (Kinder 98). The experience, once solely mine, now belongs also to the audience.

### **Platform and Form: Dual Significance**

Technology's ubiquity grants new communicative opportunities: ideas once held captive for lack of medium in which to express them are now afforded freedom. The flexibility of a web platform allows the possibility to more accurately relate significant concepts in a manner that

provides expansion and depth, adding layers and meaning beyond the flatness of text on a piece of paper. Additionally, because “subjectivity is not entirely a linguistic construct,” an interactive web platform can illustrate a fuller “glimpse of life being lived and communicated in gestures [or] sounds beyond or without the resources we usually recognize as language” (Couser 45-46). Internal reality does not consist entirely of words, but is a collage of sounds, images, and other sensory information.

As recently as 2008, in Signifying Bodies: Disability in Contemporary Life Writing, G. Thomas Couser describes, as a discriminatory perception, the idea that those with disability are “less likely to live the sorts of lives considered narratable” and “less likely to display their lives in autobiography” (32). This issue has been partly pragmatic:

*Writing* a life is an aspect of accessibility that may seem secondary, but it is pertinent...because it is peculiar to disability...the process of composition itself may be complicated by some impairments. People who are blind, deaf, paralyzed or cognitively impaired are disadvantaged with regard to the conventional technologies of writing, which take for granted visual acuity and manual dexterity. People with disabilities may be disadvantaged in ways that may not be immediately apparent to those who are not disabled (32).

It may be true that a disabled life can be considered more difficult to *narrate*, but technology has now introduced myriad ways in which anyone can depict a life. Despite practical and/or cognitive impairments, options abound for those with disability to narrate their lives both artistically and practically. Computers have leveled the playing field: autobiography for those with disabilities is now not only narratable, but with an accessible platform, the multi-dimensional experience of disability can be more fully shared. Those living with disability are

now able to “make comprehensible and mediate private interior experiences” and bring them “into the public sphere” (Hall 57).

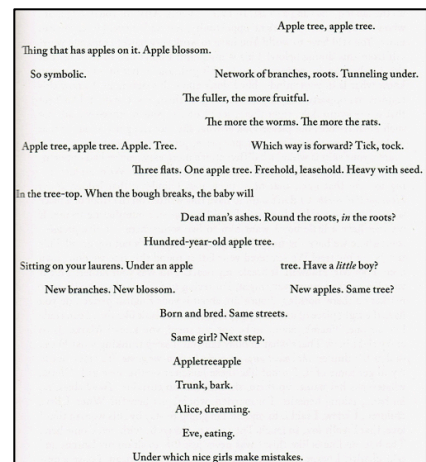
Fundamentally, this project is an expression of a truth of living with disability. Technology not only made life manageable during my illness (i.e., the availability and use of assistive programs including *Readability*, a web application that creates a comfortable reading view, as well as *LibriVox* audiobooks), but post-illness, is the vehicle in which to communicate the actuality of the experience. Its form is an integral part of its function.

There’s an inherent tension in the story I am trying to tell. It iteratively begs the audience to “keep up!” while at the same time stressing the importance of remaining patient. Its goal is to keep the audience off balance and questioning: *How do I know the experience has ended? And when it ends, do I know I am at the end? Is there ever really an end?* Again, an experience that was once exclusively mine, transfers to the audience on an emotional level.

### Literary Basis

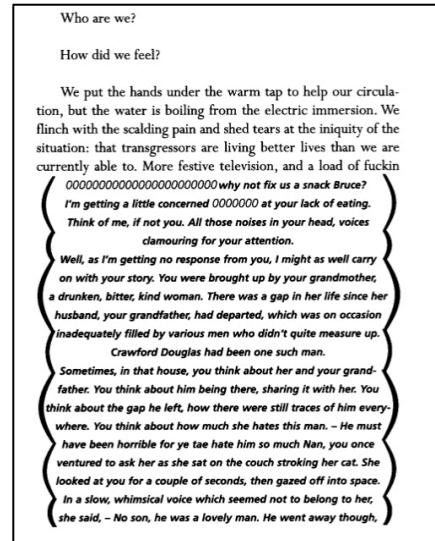
Unusual narrative structure drives the story in two recent novels: Zadie Smith’s NW and Irvine Welsh’s Filth.

Smith’s fractured and poetic freestyle writing mashes up vignettes and poetry with Google Maps and text messages. In many parts of the novel, the narrative’s form takes on the shape and structure of the content of the subject in which she writes. In the example shown, the text layout aids in telling the story. The apple tree is symbolic of the inner guilt the character faces, the sin of which she is guilty, as well as reference to the



actual tree under which she lies. Smith’s novel encapsulates a sense of place, and formatting the text in this way, the author subtly positions the reader next to the tree: in fact, the tree is now in the reader’s hands.

In his 1998 novel, *Filth*, Irvine Welsh plays with text to replicate his protagonist’s mental health deterioration. At certain points in the book, the narrative is interrupted by a tube-like structure that appears on top of the text. The reader questions whether this is intentional or perhaps a printing error? It is later revealed the interruptions are the thoughts of the tapeworm growing inside the character’s intestines. The interruption is integral to meaning of Welsh’s narrative.



In both works of literature, form and function work together to tell a story. Each author manipulates the layout of the text to evoke anxiety in the reader.

**Manipulation and Restriction**

In much the way Smith and Welsh manipulate the text in their novels to evoke an emotional response, I have attempted, in my work, to push this concept further. Not only do I manipulate text, but I am also able to manipulate the user experience. Unlike a static book format, I have moved my narrative onto the web to create another level of interplay between content and audience:

In cyberspace, interactivity wavers between two poles. While all narratives are in some sense interactive (in that their meanings always grow out of a collaboration between the individual subjectivities of authors and users and the reading conventions of

the respective cultures they inhabit and languages they speak), all interactivity is also an illusion, because the rules established by the designers...necessarily limit the user's options (Kinder 98).

My aim is to artfully control and exploit the senses through interactive experience.

In addition to the narrative form, there's also an artistic and technological form at play: each object (e.g., image, audio, video) in this project has been intentionally and thoughtfully chosen. The white text on a stark black background subverts the expected black text on white paper typical of scholarly text. The darkness also alludes to blindness and confusion, as well as not having the ability to see past the object presented. The background also provides rest and relief, when interspersed with pages filled with uncomfortable and overwhelming color.

Images of familiar objects and mundane environments have been modified. In doing so, the user is "faced with images that are to varying degrees ambiguous, indistinct, or incomplete" and he or she must "deliberately work to arrive at an intelligible interpretation, supplying possible solutions from individual cognitive resources that are then projected onto the original material" (Pepperell 395). Font size, font spacing, and font direction varies, forcing the user to question what and how he or she is seeing.

Adding to the confusion of sensory loss, an image unexpectedly becomes page navigation. In this sense, the "once-invisible artist's code has become a conscious syntax for co-creation, consisting of artistic elements, navigational rules and systems of interaction. Users physically unfold the art syntax and create unity in the work" (Buckner 4). Through interaction, the user is necessarily inserted as co-author of the art in which they are experiencing.

A few restrictive elements have been added. For instance, the project must be viewed in specific web browsers (i.e., Chrome or Safari). Sometimes the audio and video require user



input, and sometimes each plays automatically. This underscores the idea that one is not always in control. Additionally, the user is supplied only with forward navigation. This experience is meant to mimic life, where there is no back button. The only way out is through.

### **Audio, Video, and Code**

Multimedia elements are of utmost importance in this project. In an environment in which one cannot consistently rely on text or image to tell the story, audio and video ease the burden. It may seem counterintuitive to rely on video in a narrative about vision impairment, but, in this case, “the selection of particular data (characters, objects, settings, sounds, events)” helps to generate the story I wish to relay (Kinder 113). For example, the image of a seemingly unremarkable Target store juxtaposed with the kaleidoscope image of the same scene was intentionally created through programming code that could never be duplicated on paper. Additionally, in other parts of the project, hearing fills the void left when vision is no longer available. Even if one can't see the video, the audio/music/lyrics continue the narrative.

### **Conclusion: Recognition of Empathy**

“Physically interacting with on-screen elements is an empowering act, because the user becomes cause in the scenario” (Buckner 4). When a user becomes cause, there is a greater chance to invoke any of the four qualities of empathy: perspective taking, staying out of judgment, recognizing emotion, and communicating emotion. Because the audience is invested in the scenario, he or she now has a point of reference in which to base a sense of empathy. The simple awareness of knowing what it could be like living with disability is powerful. One can now use this newfound awareness in relation to his or her life. Empathy. Feeling with others. You can say that you understand, because now you have some approximation.

## Bibliography

### Text

- Bauby, Jean-Dominique. The Diving Bell and the Butterfly: A Memoir of Life in Death. New York: Vintage International, 1997.
- Buckner, Barbara. "Healing Interactions and Interactive Digital Art." AfterImage: The Journal of Media Arts and Cultural Criticism 29.3 (2001): 4-4.
- Cohen, Richard M. Blindsided: Lifting a Life Above Illness: A Reluctant Memoir. New York: HarperCollins, 2004.
- Couser, G. Thomas. Signifying Bodies: Disability in Contemporary Life Writing (Corporealities: Discourses of Disability). Ann Arbor: The University of Michigan Press, 2009.
- Detsi-Diamanti, Zoe, Katerina Kitsi-Mitakou and Effie Yiannopoulou, The Flesh Made Text Made Flesh: Cultural and Theoretical Returns to the Body. New York: Peter Lang International Academic Publishers, 2007.
- du Pré, Hilary and Piers du Pré. Hilary and Jackie. New York: Ballantine Books, 1997.
- Eliot, T.S. The Waste Land: A Facsimile and Transcript of the Original Drafts Including the Annotations of Ezra Pound. Ed. Valerie Eliot. San Diego: Harcourt Brace & Company, 1971.
- Grandin, Temple. Thinking in Pictures: and other reports from my life with autism. New York: Random House, 2006.
- Hall, Alice. "Autre-biography: Disability and Life Writing in Coetzee's Later Works." Journal of Literacy & Cultural Disability Studies 6.1 (2012): 53-67.
- Hitchens, Christopher. Mortality. New York: Twelve: Hachette Book Group, 2012.
- Kinder, Marsha. "Honoring the Past and Creating the Future in Hyperspace: New Technologies and Cultural Specificity." The Contemporary Pacific 15.1 (2003): 93-115.
- Lander, David L. Fall Down Laughing: How Squiggy Caught Multiple Sclerosis and Didn't Tell Nobody. New York: Penguin Putnam, 2000.
- Pepperell, Robert. "Seeing without Objects: Visual Indeterminacy and Art." Leonardo 39.5 (2006): 394-400.
- Rapp, Emily. Poster Child: A Memoir. New York: Bloomsbury, 2008.

Smith, Zadie. NW. New York: Penguin Books, 2012.

Welsh, Irvine. Filth. New York: W. W. Norton & Company, 1998.

Wurtzel, Elizabeth. Prozac Nation. New York: Riverhead Books, 1994.

## Digital

Dickens, Charles. Oliver Twist. LibriVox. <<https://librivox.org/oliver-twist-by-charles-dickens/>> November, 2006. Accessed July 2014.

Hardwick, Chris. "#456 Jon Lovitz." The Nerdist Podcast. <<http://www.nerdist.com/pepisode/nerdist-podcast-jon-lovitz/>> 20 December 2013. Accessed June, 2014.

Incubus. "Dig." Light Grenades. YouTube. YouTube, LLC. <<http://www.youtube.com/watch?v=nMsZ6wkZWhA>> December, 2009. Accessed March, 2014.

National MS Society. "What is MS?" YouTube. YouTube, LLC. <<http://www.youtube.com/watch?v=KGzsriXqg6U>> March, 2009. Accessed March, 2014.

Radin, Joshua. "Brand New Day." Simple Times. YouTube. YouTube, LLC. <<http://www.youtube.com/watch?v=IYqRfQ5G4as>> June, 2010. Accessed March, 2014.

## Film

Go Now. By Jimmy McGovern and Paul Henry Powell. Dir. Michael Winterbottom. Prod. Andrew Eaton. 1995.

Hilary and Jackie. By Hilary du Pré, Piers du Pré and Frank Cottrell Boyce. Dir. Anand Tucker. Prod. Guy East. October Films, 1998.

Temple Grandin. By Temple Grandin, et al. Dir. Mick Jackson. HBO Films. Ruby Films. Warner Home Video, 2010.

When I Walk. By Jason DaSilva. Dir. Jason DaSilva. Prods. Jason DaSilva and Alice Cook. 2013.