APHANTASIA: SILENCE IN THE MIND

BY

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Author's Declaration

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Abstract

Calling to mind the senses associated with our memories is something the majority of us think of as a universal experience. But what if you could not bring back the sensations from *any* of your memories? *Silence in the Mind* was performed on June 28th, 2017 at Burdock in Toronto, Ontario, Canada, as a live interactive documentary exploring those who are aphantasic: people who do not possess a sensory memory. This project seeks to understand variations on the human experience, and how we as unique individuals perceive the world around us. *Silence in the Mind*, recorded as an audio documentary, examines a newly discovered way in which some people have always experienced the world around them.

<u>Acknowledgements</u>

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I would also like to thank Elle Flanders as well as Alison Macleod for their support, advice, guidance, and feedback. My sanity would not have been there without either of you.

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Introduction

In August 2015, I picked up a contract to produce a promo video for an initiative being produced by Tom Ebeyer. Right off the bat, there were a few things struck me about Tom; he was very focused, and quite logical in his thinking. At no point was Tom distracted by anything else around him, which was amazing, and refreshing. He was always present.

Our original idea was to make the promo video a short documentary, but seeing as this was just the beginnings of this new initiative, that idea was not going to work. We needed this to be a touch more traditional, and have Tom look directly at the camera, and deliver key lines; which is nerve-racking for just about anyone who has never done it before. But for Tom it was harder than most. I have worked with actors who cannot memorize lines, but with Tom, there was something different. We eventually took a break, and Tom was talking to a friend about an interview he had done with CBC Radio's *As It Happens*. I immediately jumped in asking if it was about this project and Tom turned to me and said, "No, it's about my condition, I guess? It's called aphantasia". He then went on to explain that his condition (a word I do not like using to describe this) was only coined that month, and had barely been studied, but it was something that prevented him from imagining.

I felt confused, yet curious; he then told me to close my eyes and picture a horse, and really think about where the horse is and what it is doing. So, I did, and I told him that I pictured a brown horse in a field, with an old wooden fence in front of it. Tom jumped in, and then told me these exact words: "I can't do that. I don't have that

visual system, not for thoughts, not for anything. But it's more than that, I can't imagine anything, smells, sounds, tastes, or feelings."

The rest of our shoot was a blur, because all I could think about was aphantasia, and what this meant for him. The entire drive back home my friend Victoria, who was helping with me the shoot, and I could not stop talking about it. So many questions came to mind. How does he remember things? Does he re-experience things for the first time, every time? Could he be crazy? He cannot remember feelings, is he a psychopath? We just kept on speculating. Later that night, I could not fall asleep, because I was completely enthralled, I needed to learn more, I needed to sit down and interview him.

Chapter 1 · Silence in the Mind and its characters

Silence in the Mind is an audio documentary, recorded as a live podcast, exploring the variation of the human experience known as aphantasia. The piece features interviews with one main character, three secondary characters, and is narrated by me, Paul Aflalo.

At twenty years old, **Tom Ebeyer**, discovered the way he perceives the world is completely different than most of the people around him. He is aphantasic, someone who does not possess a sensory memory. He cannot visualize anything in his mind, nor can he imagine sounds, tastes, or smells. He does not possess the ability to bring back any of the senses, including feelings from memories. Tom is now 27 years old. He is originally from Mississauga, Ontario, and eventually moved to Waterloo, Ontario, where he graduated from Wilfrid Laurier University. He has a strong passion for social innovation in business and society. Tom holds a Bachelor of Arts in Entrepreneurship and Social Innovation.

Professor Adam Zeman does specialized clinical work in cognitive and behavioural neurology, including neurological disorders of sleep. His research interests include amnesia associated with epilepsy and disorders of visual imagery. He has an active background interest in the science and philosophy of consciousness, publishing a wide-ranging review of the field in *Brain* (2001) and an accessible introduction to the subject, intended for a general readership (*Consciousness: a user's guide*, Yale University Press, 2002). He has recently written an introduction to the brain for the general reader, *A Portrait of the Brain* (Yale, 2008), and edited *Epilepsy and Memory* (OUP, 2012) with Marilyn Jones-Gotman and Narinder Kapur. He was Chairman of the

British Neuropsychiatry Association from 2007-2011.¹ Professor Zeman was the one who coined the name of this variation of the human experience, now known as aphantasia.

Ron Ebeyer is Tom's father. Katelyn Ebeyer, known as Kate, is Tom's younger sister. Tom and his father have a distant relationship, whereas Tom and his sister are very close, and always have been.

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¹ Debbie Robinson, 2017. "People - Medical School - University Of Exeter". *Medicine.Exeter.Ac.Uk*. Accessed on June 2, 2017. http://medicine.exeter.ac.uk/research/healthresearch/cognitive-neurology/theeyesmind/people/.

Chapter 2 · What is Aphantasia?

Coined by Adam Zeman, Professor of Cognitive and Behavioural Neurology at the University of Exeter Medical School, aphantasia is the suggested name for a "condition" where one does not possess a functioning mind's eye and cannot visualize imagery, or any sensory memory. Those who are aphantasic, do not possess the ability to remember the senses that come with memories, such as sounds, images, tastes, smells, or feelings. The phenomenon was first described by Francis Galton² in 1880, but has remained largely unstudied since. Interest in the phenomenon renewed after the publication of a study by Professor Zeman's team.³

This began in 2005 when Professor Adam Zeman was referred a patient by one of his colleagues at the University of Edinburgh.⁴ After having a minor surgery, this 65-year-old retired building surveyor had lost the ability to conjure images in his mind. Intrigued by this, Professor Zeman and a colleague ran a series of tests on the retired surveyor, dubbed MX, and eventually published a paper about their findings and

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² Francis Galton was the cousin of Charles Darwin, and was very much intrigued by Darwin's work on the origins of species. Galton devoted most of the rest of his life to exploring the difference in human populations and its implications, at which Darwin had only hinted. (Rutherford 2015) (Contributors n.d.) Galton is a problematic figure: while simultaneously a great scientist, he was also ridiculed for his spurious later research, which set out to prove the superiority of Caucasians based on the shape of their skulls. Needless to say, he was a white supremacist. He coined the phrase "nature versus nurture," which has persistently damaged discussions of genetics, implying that these two factors are in conflict, when in fact they are in concert. It was Galton who gave us the word "eugenics". While Galton spawned a field with the intention of revealing essential racial differences between the peoples of the world, his legacy – human genetics – has shown he was wrong. Modern geneticists are much less like Galton and more like Darwin.

³ Adam Zeman, Michaela Dewar, and Sergio Della Sala, "Lives without imagery – Congenital aphantasia," *Cortex* 73 (December 01, 2015).

⁴ Adam Zeman, Interviewed by Paul Aflalo, Exeter, United Kingdom. February 2017.

research on MX.⁵ The paper was then picked up by Carl Zimmer, a journalist who was himself fascinated by the piece and the study, and had his article published in *Discover* Magazine.⁶ This in turn led about twenty people to Professor Zeman, all of whom claimed to have lacked the ability to visualize their entire lives. Professor Zeman was undoubtedly curious about each of these people that had reached out to him, and replied back with a letter asking for their help in his research, stating:

We have been studying imagery in normal folk to follow up our work with MX. We anticipate putting the data we have gathered from these participants together with what we learn from your answers to write a paper drawing attention to the neglected phenomenon you have described. Looking to the future, as we now have tools to study the working brain in action, it should soon be possible to discover why there is such a wide variation in the vividness of imagery. Your responses will highlight the variation we need to explain.⁷

Once they completed their initial research, they published another paper where they coined the term aphantasia which is based on the Greek word phantasia, that Aristotle used to describe the power that presents visual imagery to our minds. So, aphantsia means without the ability or power to describe visual imagery or sensory information from memories.

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⁵ Adam Zeman, Sergio Della Sala, Lorna A. Torrens, Viktoria-Eleni Gountouna, David J. McGonigle, and Robert H. Logie. 2010. "Loss of Imagery Phenomenology with Intact Visuo-Spatial Task Performance: A Case of 'blind Imagination'." *Neuropsychologia* 48 (1): 145-155.

http://resolver.scholarsportal.info/resolve/00283932/v48i0001/145 loipwitpacoi.

⁶ Carl Zimmer. "The Brain." *Discover Magazine*, March 2010, pp. 28–29.

⁷ Adam Zeman, Dr. to Non-Imagers. March 01, 2010. Exeter, UK. (See Appendix A.)

⁷ Carl Zimmer, "Picture This? Some Just Can't," *Science* (The New York Times), June 22, 2015, http://www.nytimes.com/2015/06/23/science/aphantasia-minds-eye-blind.html.

Tom Ebeyer and Aphantasia

Tom's personal discovery of being different came about before aphantasia was a recognized phenomenon. It was before Professor Adam Zeman had coined the term, and it was before any of his research was spread so publicly. There were some people that just did not believe him, including in his own family. His father in particular thought it was an excuse he was using to explain away why he was not doing so well in school. His sister, on the other hand, did believe him, but it was really hard for her to understand it all. The reality is, anyone who can visualize, who can experience all the senses in their mind, will never be able to imagine what it is like not be able to imagine, because we are forever imagining.

I imagine aphantasia to be a quiet serene darkness in my mind, but also where the only thing I am experiencing is the moment at hand. There are no distractions coming from my mind, I am completely present in the moment. When I mentioned this to Tom, he said he kind of agreed, but it was hard to explain.

There were times when Tom was convinced he was legitimately crazy. That changed when Tom came across Carl Zimmer's initial article in *Discover* Magazine. He reached out to Professor Zeman and his team the moment he read it. Tom was one of twenty people who reached out, and participated in their research post MX. He was finally coming to a place where he was not alone, and truly felt that he was not crazy.

Perception and Aphantasia

We, as human beings, receive perceptual information and our brain interprets what we are experiencing. If we are exposed to the same thing, what we experience

could be the same, but could be different. Take for example when we see something we know and recognize; that information is passed through our eyes and sent to the brain. Our brains then decipher the message that is being sent to us through the eyes, and we establish that we recognize it, and know what it is.

Everything we do revolves around sensory experiences. We begin with sensation, which refers to the responses of our sensory receptors and sense organs to environmental stimuli. Perception, on the other hand, is a process which involves the recognition and interpretation of stimuli which register on our senses. Perception relates to how we make sense of our environment and sensation refers to the basic stimulation of the sense organs. Imagine that you hear someone play a few notes on the piano, if you recognize that the notes form a tune, then you have experienced a perception. This is the very basics of the science of perception, we explore through the senses, and then interpret that through the brain.

Philosopher Merleau-Ponty argues that while science is important to perception, it is a result of what we have experienced directly. To use his example, we can understand geography only because we know what it is to experience a landscape.¹⁰ Perception is how we experience the world, with ourselves in it, and a part of it.

Knowledge about the world, about the objects in the world and the relations between them, must come ultimately from the individual experience of human beings. 11 Our account of the world is given from our own point of view. Some things are nearer

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⁹ Paul Rookes and Jane Willson. *Perception: Theory, Development, and Organisation,* Routledge, 2000, pp. 1–2.

¹⁰ Eric Matthews. *Merleau-Ponty: A Guide For The Perplexed*, 2006, pp. 16.

¹¹ Ibid, pp. 25.

to us than others, some are experienced as above others, or to the left or right of others, and all these features of the world as experienced depend on the relation between our position and that of what we see. The way I experience a tree that is 100 feet tall (I being 6 foot), versus how my five-year-old nephew experiences it, him being much shorter than me, is completely different. We are seeing the exact same tree, we both know that the tree is 100 feet tall, but because he is smaller than me, he perceives the tree to be larger.

The way in which aphantasics perceive the world is different. At the onset, it is the same; they take in sensory information and transmit it to the brain, just as we all do. But how they *retain* that information is what makes them, and their experiences different.

For aphantasics there is no sensory memory being stored in the brain, at least that we know of. It seems as though aphantasics remember things logically.¹³ For example, if Tom or any aphantasic saw a brown horse with white spots on it, when that horse is no longer in their view they would not be able to tell you what that horse specifically looked like. However, Tom could tell you what a horse is *supposed* to look like. He might even remember that the horse was brown and had white spots, but as Tom is describing this horse to you, he is not seeing anything in his mind. He just remembers logically what it was that he saw.¹⁴

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¹² Ibid, pp. 28.

¹³ Adam Zeman, Interviewed by Paul Aflalo, Exeter, United Kingdom. February 2017.

¹⁴ Adam Zeman, Michaela Dewar, and Sergio Della Sala, "Lives without imagery – Congenital aphantasia," *Cortex* 73 (December 01, 2015):, doi:10.1016/j.cortex.2015.05.019.

Ever since Tom was a young child, he hated tomatoes, so since then he has avoided them. After he realized that he was aphantasic, a friend of his made him try a tomato. Remember, because there is no sensory information that comes with his memories, Tom cannot remember what things taste like. He just knows logically, that this one time he tried a tomato, and did not like it, therefore he does not like tomatoes. But as we grow, our taste buds diminish, and become less sensitive, so because of this something we might not have liked as a child we might enjoy now. ¹⁵ So, Tom tried the tomato, and surprisingly to him, he liked it. But, because Tom remembers things logically, without any sensory information, convincing himself that he likes tomatoes has become a challenge. He does remember eating it and liking it, but because he does not have a sensory experience from that memory, he cannot relive that experience and remember what it tasted it like. This makes it much harder for him to remember that he now likes eating tomatoes.

In 2012, Doctor Fiona Macpherson wrote a paper in which she explored cognitive penetration, which is when your beliefs or desires affect your perceptual experience. She explains that cognitive states cause some visual imagining in the mind to occur. Things like a scent can cause you to imagine and dream of a place from where you remember that very smell. Then you start imagining that space, and then that could lead you to other memories that occurred there. This relies on the content of

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¹⁵ Leonard Hayflick. "HUMAN CELLS AND AGING." *Scientific American* 218, no. 3 (1968): 32-37. http://www.jstor.org/stable/24925997. (Hayflick 1968)

your visual imagery, and often relies on the personal experiences you have experienced before.¹⁶

Traumatic memories can haunt us. We hear often of people who suffer from post-traumatic stress disorder, where they find themselves reliving past traumatic memories. These memories are triggered by the senses; a sound, a scent, touch, taste, or something they even saw. Many people who suffer from PTSD will try to push their memories away, and hide from them, instead of dealing with them.¹⁷

When Tom was seventeen, his mother died unexpectedly. He was sad and depressed for a long time. But after he pulled through it, and was no longer sad and depressed, it was over. He can never go back and relive that experience again. He knows that it happened, he knows that he was sad and depressed. But when he thinks of those moments, they are just a logical memory of a series of events, without any emotional or sensorial attachment.

While there is no concrete evidence of this yet, there is a large possibility that aphantasics cannot suffer from post-traumatic stress disorder. So, for those who can imagine, try imaging a life where your past memories cannot come back to haunt you. But also flip that around, imagine a life where you can never relive any of your happy moments either.

What pulled me into wanting to learn more about aphantasia was the emotional impact our memories have on us, more specifically people like me, who have a sensory

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¹⁶ Fiona Macpherson. 2012. "Cognitive penetration of colour experience: Rethinking the issue in light of an indirect mechanism." *Philosophy and Phenomenological Research* 84 (1): 24-62.

¹⁷ Jonathan I Bisson. "Post-Traumatic Stress Disorder." *BMJ: British Medical Journal* 334, no. 7597 (2007): 789-93. http://www.jstor.org/stable/20506896.

memory. My emotions, and the feelings from past memories drive me. Those experiences, and the memories of them, shape me. They help me gain a better understanding of how I perceive myself, but also how I perceive the world around me.

2015: Aphantasia exists

With the new paper from Professor Adam Zeman in hand, Carl Zimmer wrote a new article, this time for the *New York Times*, ¹⁸ which reached millions of readers around the world. One of them was Blake Ross, who discovered through Zimmer's second article that he was aphantasic. Ross then sat down and wrote his own piece which he self-published on Facebook. In it, he describes his own personal experiences being aphantasic, but more importantly his awe in the initial discovery. Like Tom, Blake Ross has never visualized anything. He cannot see his father's face, or envision a bouncing ball, his childhood bedroom or something he might have done a few minutes ago. Like many aphantasics, he thought counting sheep, to help you fall asleep was a metaphor. At the age of 30, Blake Ross discovered that there are many people out there, in fact the majority of people, who can do all of this, and it completely flabbergasted him.

According to Professor Zeman, those who are aphantasic are not disabled, they are not psychopaths or sociopaths, nor is aphantasia a "condition". Instead, he describes aphantasia as a "variation of the human experience," similar to that of synesthesia where about ten out of a million people are born to a world where one

¹⁸ Carl Zimmer, 2015. "Picture This? Some Just Can't." *New York Times.* https://www.nytimes.com/2015/06/23/science/aphantasia-minds-eye-blind.html

sensation involuntarily conjures up another. Sometimes, all five clash together, along with a feeling of movement. That makes for six separate sensations that can mesh.¹⁹ Imagine a world where the colour yellow has a specific smell, or apples feel square. In *The Man Who Tastes Shapes*, Doctor Cytowic opens with Michael, a patient who is a synesthetic, who describes the way he tastes, while in the midst of cooking a chicken: "Flavours have shape.' he started, frowning into the depths of the roasting pan. 'I wanted the taste of this chicken to be a pointed shape, but it came out all round.'" Much like aphantasia, synesthesia went un-researched for over 200 years.

Perception begins with the individual, it is about how the individual experiences the world around them. We are not all the same, we experience things differently. But when we exchange these individual experiences and perspectives, we begin to have a better understanding of the world around us. Our uniqueness in how we experience the world, allows us to come together to create a larger understanding.²¹ When we encounter such big perceptual differences in human beings, like synesthesia and aphantasia, we start to question how it is that they are different, but rarely do we question what makes us different. We look at ourselves as being "normal," and them as different. But, from Tom's and other aphantasic's point of view, could they not also perceive themselves as normal? This is why I do not like calling aphantasia a "condition," because we experience the world differently, and neither perspective is necessarily wrong.

¹² Richard E. Cytowic, *The Man Who Tasted Shapes* (Cambridge, MA: MIT Press,

^{1998),} pp. 4-5. ²⁰ lbid, pp. 4-5.

²¹ Eric Matthews. *Merleau-Ponty: A Guide For The Perplexed*, 2006, pp. 35.

Just the beginning of Aphantasia

While initial research has only begun, and we are a long way away from any concrete discoveries, there are some things that Professor Zeman's team has speculated about. For one, there is a chance that aphantasia could be genetic, and is carried through family genes, which is partially backed up by some of my own research. I have come across many people over the last year through various online forums discussing aphantasia who have direct relatives: parents, siblings, blood related aunts and uncles, cousins, even half-siblings, that are also aphantasic. One person in particular, Laura, told me that not only is she aphantasic but she also has prosopagnosia or face blindness. She also has four children, one of which has prosopagnosia, and another that is also aphantasic. So, there is a great possibility that aphantasia has a direct relation to our family genes.

There is also a spectrum of aphantasics. So, for example, there are some people who can retain the memory of sounds or smells, but might not be able to retain the image or feeling of a memory. Before passing away, Oliver Sacks had reached out to Adam Zeman, and told him that he was aphantasic, but could hear sounds and music in his mind. Yet, most people who are aphantasic have no sensory memory at all, like Blake Ross and Tom Ebeyer.

Chapter 3 – Methodology

Podcasts and Radio

From the very beginning, even before deciding to produce this project. I knew I wanted my MRP to be an audio documentary, and even more so a podcast. While the origins of podcasts come from radio, they can be produced and distributed without being broadcast on radio. Podcasts are distributed online through RSS feeds, that can connect easily to iTunes, Stitcher, Google Play, Spotify, and more. Unlike radio, you are not limited by the "clock"; when a show has to be seventeen minutes on the radio, it has to be that and no more or less. That is not the case with podcasts.

The do-it-yourself nature of podcasts makes it more accessible for creators to produce their work, and skip "the middle man," in this case radio, and get it out to an audience. However, finding your audience is the hard part. Radio stations have their audiences, they also have people who are constantly tuning in who can easily fall upon a program. Radio programs are also available as podcasts, but in turn podcasts can be broadcast on the radio. In fact, you find this with podcasts like *Canadaland*, ²² which is a podcast first. Also, most CBC produced podcasts, are featured on the radio.

Origins

Before anything, I am a storyteller. Storytelling is the foundation of the work and art I create. The reason that I create is because I want to share stories. Personal stories are the ones I am most attracted to and attached to. Years ago, I began co-producing

²² Jesse Brown. 2017. "On The Radio - CANADALAND". *CANADALAND*. http://www.canadalandshow.com/radio/. Accessed on August 17, 2017.

Confabulation, a monthly storytelling series in Montreal, Quebec. (Confabulation has since grown, and we now have shows in Toronto and Victoria.) Each month, we invite six storytellers to share a true story about themselves without notes, props, or gimmicks. It is meant to feel open, raw, and authentic, but also simple. It is essentially documentary, but on stage. I got involved because of my curiosity to share stories, and also because of podcasting, and the narratives that are weaved through audio.

The first time I listened to a podcast was when I had just moved into a new apartment. It was 2005, and I was in the midst of setting up my home office, and wanted to keep everything that had to with the internet in a closet, but the wires could not fit under the closet door, so in my deep wisdom I decided to drill a hole through the wall leading from my office directly into the closet. My friend Adrienne had been bugging me to listen to This American Life for months, and I decided that that moment seemed like the perfect time to load it up and take a listen. So, I picked an episode at random (I had downloaded a few), hit play, and started to drill through the wall. The story that opened the episode was about a police officer named Paul Bacon. One night he was pulling a second shift when he had a perfectly good idea: He'd stretch out in the back seat and take a little nap during his break. He fell right asleep, and slept well until he woke up and realized the funny thing about the back seats of cop cars: the doors don't open from the inside.²³ Now, I am loving the story; the notion of a police officer being so clueless, to me is hilarious. As Ira Glass, the host of the show, starts introducing the title of the episode, "Seemed Like a Good Idea at the Time", that is the

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²³ "Seemed Like a Good Idea at the Time," This American Life, January 13, 2006, accessed December 15, 2016, https://www.thisamericanlife.org/radio-archives/episode/306/seemed-like-a-good-idea-at-the-time.

exact moment that sparks came flying off my wall, and the power cut out in the room. I had stupidly been drilling the hole right next to the power plug. The irony of what I was doing, and what I was listening to is, and was, not lost on me. Neither is the irony of producing an audio documentary, a medium which requires you to imagine and visualize things in your mind, about a phenomenon (or variation of the human experience) which prevents you from doing just that.

While recognizing this, I also feel that audio is the perfect medium for this story. I know it is impossible for us to imagine what it is like not to imagine, but this project is all about how we perceive and imagine the world around us. When Tom asks me to picture a horse, he wants my eyes closed. He wants me to use me my imagination. Having people see images in front of them pulls you away from that very experience. I am carefully weaving together different voices, thoughts and ideas into one story, that has to ignite your own imagination, giving those who can imagine, a chance to think of the unimaginable as beautiful.

In an interview with the website *Big Think*, *Radiolab*'s Jad Abumrad said this about audio storytelling: "in a sense, I'm painting something but I'm not holding the paintbrush. You are. So, it's this deep act of co-authorship, and in that is some potential for empathy. I think, that somehow, we are doing it together because we have to fill this gap of pictureless-ness together. We have to somehow be connected. I love that about radio and podcasts."²⁴

²⁴ Jad Abumrad, *How Radio Creates Empathy - Video*, April 3, 2012, posted December 15, 2016, http://bigthink.com/videos/how-radio-creates-empathy.

Audio pieces allow for an intimacy that is unique to the medium, and with podcasts, even more so. 64% of podcasts are being listened to on a smartphone or tablet. When I am listening to a podcast, I am either in my car driving, or while walking, cycling, or taking public transit. If it's the latter, my headphones are on, and those podcasts are in my ears, talking to me directly. So, how we perceive this auditory experience greatly differs from film or any other form of visual storytelling. We are using our ears and our imagination to ignite what we are listening to. By not having to focus on anything visual outside of our inner mind, this allows us to multitask. I cannot drive, walk, or cycle and watch a movie, because we need to see what were are doing, but I can do all of those while listening to a podcast.

This American Life reminded me why I loved storytelling, and pulled me into narrative based podcasts. Radiolab made me want to create narrative podcasts. Radiolab is a show about curiosity. Where sound illuminates ideas, and the boundaries blur between science, philosophy, and human experience. Radiolab has designed a show for sustained and undivided attention. It wrestles with big, serious ideas like, time and deception. It ignores the news cycle completely. And it expects you to stop checking your inbox, updating your status or playing Angry Birds and spend a solid hour listening. This show encapsulates you, the sound design challenges your ears,

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²⁵ Jay Baer. "The 5 Key 2016 Podcast Statistics." May 2016. Accessed December 15, 2016. http://www.convinceandconvert.com/social-media-measurement/the-5-key-2016-podcast-statistics/.

²⁶ Radiolab. "About." 2016. Accessed December 15, 2016. http://www.radiolab.org/about/.

²⁷ Rob Walker, "How 'Radiolab' Is Transforming the Airwaves," *Magazine* (The New York Times), September 7, 2014, http://www.nytimes.com/2011/04/10/magazine/mag-10Radiolab-t.html.

and makes you feel differently about radio, and audio documentaries. I love the fact it forces me to listen; I embrace it. For me, *RadioLab* is an audio show that pulls me in, and forces me to imagine the world they are creating. This is what I want to re-create, (not the way they produce audio), but the way they tell stories.

Research

This project began before it was ever going to be my thesis project. After discovering Tom Ebeyer's aphantasia, I immediately became intrigued and fascinated by it. I knew then I had to produce something about it. This project only became my thesis project when my original idea fell through, and at that point Tom and I had recorded three interviews, so it seemed only fitting for this project to become my thesis research project.

There is also a remarkable exploration to be had with Tom's story. This project does not just question what it means to be aphantasic, but it asks us to question how we as humans, interact and experience the world that we are part of. I use my imagination consistently. It helps me create, produce, remember, and experience the world. I remember that I hate olives by conjuring it's taste and smell. It allows me to dream and fantasize. Knowing that there are people out there that cannot do that, does not just blow my mind, but leads me to understand how they perceive things.

Aphantasia is new. Even though the first recorded mention of "mental blindness" was in the 1800s, there has been very little scientific research done up until now, so it's still very much unknown. The only references at the very beginning of this project were

Tom, the initial scientific paper released by Professor Adam Zeman and his team, the few repetitive articles that have covered aphantasia, and also word of mouth experiences from people online through forums and Facebook groups.

There was (and still is) a lot of trust between Tom and I, which allows for this piece to feel authentic and real. Tom's willingness to not just participate, but also to explore aphantasia, made the journey much simpler, and more complete. After all, it was his own intrigue and discovery that led to him talking about it so much, and then led to me finding out about it.

Eventually, I stumbled across other people who are quite prominent that are also aphantasic such as magician and performer *Penn Jillette*, of *Penn and Teller*. As well as Blake Ross, the founder of Mozilla and the browser Firefox. I reached out to both. Blake Ross wrote back asking me to refer to his lengthy article he published on Facebook, and I never heard back from Penn Jilette. (Filmmaker Ric Esther Bienstock warned me that getting a hold of him would be very hard, if not, impossible.)

Not long after, I came across a Facebook group of people who are aphantasic. This opened a very interesting conundrum, in that it was here I discovered that there is a spectrum within aphantasia; where some people are capable of recalling and bringing back sounds or smells or images or emotions, but cannot bring up other senses. (This was later confirmed by Professor Adam Zeman, at Exeter University.)

This also begs the question of whether those who can experience and recall some of the senses but not others, are truly aphantasic? We have yet to find out. But it does open another door into how those people perceive and experience the world they inhabit.

Finally, meeting Professor Adam Zeman in the UK allowed for a more complete understanding of how everything unfolded and what his research up until this point entailed. From our last conversation, he mentioned they had completed a study in sixty people, those who are aphantasic, those who are "normal", and those who are hyper visualizers, people who have a photographic memory. Now they are beginning a series of scans and tests on those who are only aphantasic. He also mentioned that there are other researchers and doctors that have taken on aphantasia around the world, and are exploring it as well.

Millions of pieces

I love producing. I love directing. I love conceptualizing new ideas. I like interviewing. I like imagining what could be. I am a storyteller, and that is where all of this stems from. But holy hell do I hate editing. Okay, maybe that is not entirely true; I like editing when looking at the overall as a producer in a film would do, but doing the actual editing; sitting in front of the computer and cutting things and moving them around... I find it to be tedious and boring.

But for this project I decided to challenge myself to edit it all. Needless to say, this part has been the hardest; and not just because I hate editing. My experience in podcasting stems from simple interview style shows. Raw, open, and very little editing involved. It allows for faster turnover, and also keeps things simple. But while working on this piece, from day one, I wanted it to be narrative driven. I wanted to tell a story, and even though I do come from a storytelling background, most (if not all) of the stories I share on stage are personal, and about me. Here, I am telling someone else's

story; mixing it with his voice and the voices of other people, as well as my own. So, not only am I delving into something unknown, I have been challenging myself to work in a completely new way, and while at times I have hated it, there have been other times where I have loved it.

Before most of the recording was done, I was exploring different ways in which I could present the podcast. At first, I thought one long audio documentary would be nice and simple. Then, a suggestion was made to divide it up between the senses, where there would be an episode for sight, sound, taste, smell, touch, and finally emotion. But as the documentary started coming together, I started to realize that before anything, I needed to give the audience a clear understanding of what aphantasia is, and allow them the time to process it, because it is not easy to wrap your head around. Unlike other variations of the human experience, we only know a tiny bit about it, so this leads to more and more questions that are not always easy or even possible to answer.

Realizing all of this, it became clear that this audio documentary, this podcast, would have to be an exploration into aphantasia that included the audience allowing them to understand it, by exploring aphantasia through their own senses. To do this, it would have to be a live interactive performance, that was recorded so anyone could experience it later.

A live experience (June 28th, 2017 – Burdock in Toronto, Ontario)

Once the decision was made to have this be a live podcast recording, with interactive elements, I thought of two places where this could work beautifully. The

initial idea was to have the event at a venue that is made for performances. And while that is what I did do in the end, there was a brief moment, when I considered presenting it in large Foley studio at Ryerson University. I really liked the idea of bringing everyone into a studio to be part of a behind-the-scenes recording experience. But in order to give them a full sensory experience (outside of just sound, and visual), I realized it would be best to present this project in a venue, that could allow for everything.

Burdock, a venue in Toronto, Ontario, was the chosen venue. After building a strong relationship with them over the course of a year by having *Confabulation Toronto* there, it was a natural choice. Plus, they designed the entire space to be completely sound proof, and their sound technicians are also trained sound and music producers who know how to record live shows beautifully. So, by doing it at Burdock, it allowed me to have that same studio experience, but in a venue that was attuned to everything else I needed, and wanted to do.

The performance of the live show included four main components: the recording of my voiceover and narration, the pre-recorded and edited interviews, and the music. All of the latter were cued and played by me through my computer. Part of the experience for the audience included them knowing I was the one controlling the whole show from the stage, as I was taking them through the story.

Part of the performance, but not at all as scripted, were the interactive elements.

As I mentioned in the introduction, the very first time Tom told me about aphantasia, he asked me to close my eyes and picture a horse. This is how Tom has opened every conversation he has had with someone that has never heard of aphantasia. So, before

the show even began, I felt it was only fitting to do that same exercise with the audience, but without them really knowing why. They then wrote or even drew what they had imagined, on small pieces of paper, which I collected for use later in the show.

Posted all around the venue were QR codes with a link to a photo of my father. (I had not seen that photo since January 2017, and as I mentioned earlier my father died when I was six years old, so it's not like I have seen him since.) I opened the show by calling my sister Jessica, who was in Montreal, Quebec, from the stage. With my sister looking at the photo, along with the audience, I then did my utmost to describe it from memory; something that would be nearly impossible for an aphantasic to do, and might not be so easy for others to do. I remember doing an okay job, but there were some things I definitely got wrong.

At another point during the show, I had my friend Annalise come on stage and try to describe the taste and flavours of a strawberry, while the audience and I had a chance to eat them. In fact, I encourage you, without eating a strawberry, to try to describe what a strawberry tastes like. It is not easy.

Towards the end, I brought Tom on stage, where we explored and "experimented" with him. Outside of us both eating olives (and still hating them), I had Tom try to reproduce someone else's accent, which he could not do. Remember, he cannot hear the voices of anyone in his mind, so trying to emulate something you cannot hear in your mind is likely impossible. He was, however, able to hum the beat to two of his favourite songs. And finally, we ended the show with a Q & A from the audience, which was probably my favourite part of the whole show. It allowed the

audience to pose their own questions and discover more about something they were completely unfamiliar with.

I will admit, I only remember all of this after listening to the whole recording. The entire night was a blur for me. I am rarely nervous on stage when performing, but for some reason, that night I was sweating bullets. In hindsight, I realized it was because I was not presenting a part of me, but sharing Tom's life with the audience, but more importantly, him. He was there, the entire time sitting in the front row, listening to every word.

Feedback throughout the process

While there is an argument to made that storytelling is storytelling regardless of format, the reality is that working solely with audio has been a challenge. I am not relying on images to compliment what is being said. I have to paint the picture for those to imagine. Even harder, is painting a picture for those who cannot imagine.

While the faculty of this program have their own expertise, none of them have experience working solely on audio-based projects, let alone audio-based narratives. So, when presenting my work to my professors and colleagues, the feedback had not been the greatest experience, or entirely useful. So, to help and challenge me, I had reached out to professionals, and others who have the experience I needed to move this project forward.

Where the expertise of the faculty excelled was pointing out what was clearly obvious to them, perception. Not as well versed in theory, I did not fall upon this until

speaking with Elle Flanders. This is something that not only helped the project, but gave it a larger scope.

I also have to admit that I had an advantage by producing a podcast. If there is anything I felt was missing, that I desperately needed to have in my project, recording new interviews is much easier when your project is audio-based.

Chapter 4 · Documentary Relevance

Silence in the Mind is rooted in three different forms of documentary. The first is the oral tradition of storytelling, the second is audio documentaries through podcasting, and the third is live interactive performance. Each of these elements come together to share a narrative that was unpacked and presented as a live performance, but also recorded so that anyone could listen to it later on.

This entire aphantasic experience is woven together through the stories from five voices. The first is Tom Ebeyer, the main character to whom you are introduced through a personal experience with aphantasia, the second is Professor Adam Zeman, the authority on aphantasia, the third and fourth are Tom's immediate family, his father Ron Ebeyer and his sister Kate Ebeyer. The fifth voice is my own as host and narrator throughout the podcast. My voice brings everything together, and connects each point to tell the story as a larger narrative that is the audio documentary.

Storytelling is at the heart of the piece. In fact, storytelling was of the earliest means of communication. Throughout the early development of human beings storytelling was a great medium for sharing experiences, for teaching, and for handing down from one generation to the another our ideas, ideals, values, and standards of behaviours. It was also, and still is, a superb form of entertainment.²⁸

Storytelling is something we do every day with the people around us. We share our experiences, what happened to us, how it all un-folded, and the impact it had on us. Essentially we are made of stories. Telling stories is sharing life experience, real and imagined. So, stories are told by everyone with experience to share with those who

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²⁸ Tooze, Ruth. 1964. Storytelling. Englewood Cliffs, N.J.: Prentice-Hall, pp. v.

have ears to hear. The teller and the listener together create the story; like a song that lives only when it is sung and heard, a story lives only when it is told and heard.²⁹ Documentary embodies storytelling, and without it you lose a critical element in sharing and conveying your message. Building narratives to push your message is one of the most effective ways to reach people and help them understand what is being said.

But simply sharing a story is something anyone can do. We do it all the time. Crafting a story carefully, weaving it together to convey a message to an audience that is there specifically to listen to it, requires many factors. First, you have to enjoy telling the story; you need to know the story inside and out, it needs to be a part of you, especially when it is not your story.³⁰

This translates beautifully in the stories I am sharing. Tom's initial discovery and exploration of what became aphantasia is a remarkable story of internal reflection and questioning. Tom sharing his story with his father and sister brings them into his narrative. They not only question Tom's internal beliefs, but also question what they have known and understood about the way we perceive and imagine the world. Next, is Professor Adam Zeman's initial discovery with his patient MX, and also the later revelation, and naming, of aphantasia. All different stories, weaved into one narrative.

Documenting through Podcasting

From storytelling, we move naturally into podcasting, the initial chosen format for my piece. But more importantly, the style of podcasting and radio that was inspired

²⁹ Ibid, pp. vi.

³⁰ Ibid. pp. 31.

by the format pioneered by This American Life, which began as a radio show called Your Radio Playhouse in 1995.31 Before developing the show, then reporter Ira Glass was still learning how to piece together his work as a new reporter for the U.S.-based National Public Radio (NPR).³² A turning point for him was when he realized that every story had to have some moment where he was in the tape, talking to someone. He did this because he had noticed that in other people's stories, the most interesting stuff usually came when they interacted with the people in the stories, where there was a back and forth. It allowed for a different kind of drama in the stories, the drama of someone being charming or dogged or wheedling or funny with another person. He openly admits that that style of interview did not come naturally to him.³³ But, this interaction has created an intimacy and authenticity that was more real for the listener. This way of creating radio was not just about sharing the news, but sharing experiences; allowing you to eavesdrop on the conversation. I have heard people say many times, that they wish they could have been a fly on the wall in a conversation they were not privy to. This type of interview and radio makes you feel like you are that fly on the wall.

This type of journalism inspired new ways to share true stories, and spawned a style of podcasting that has encapsulated listeners around the world. Most notably,

³¹ Ira Glass and Torey Malatia. 2016. "This American Life". *This American Life*. https://www.thisamericanlife.org/. Accessed on December 2, 2016.

³² "National Public Radio (NPR)". 2017. *NPR.Org*. United States national public radio, with stations throughout the US. http://www.npr.org/.

³³ Glass, Ira. "Harnessing Luck as an Industrial Product" Excerpt From: John Biewen. *REALITY RADIO: telling true stories in sound*. 2nd ed. S.I.: UNIV OF NORTH CAROLINA PR, 2017

podcasts like *RadioLab*, *Reply All*, *Embedded*, *Snap Judgment*, and of course *Serial* and *S-Town*, both of which are produced by *This American Life*.

While there are many podcasts and episodes that I have learned from and relate my work to, the two that stand out are episodes from *This American Life*. In fact, they are two-part episodes in which the producers from *This American Life* followed the students, teachers and administrators at Harper High School in Chicago, Illinois, for five months at the start of a new school year, where later in 2012, 29 current and recent students tragically were victims of gun violence. They went there to get a sense of what it means to live in the midst of all the gun violence, how teens and adults navigate a world of funerals and Homecoming dances.³⁴

These two episodes documented remarkable personal stories from all corners of the high school, not just focusing on the students or the faculty or the administration. They wanted to, and succeeded, in sharing the stories from all of them. This allowed for a richer experience, and a better understanding of all their lives. But what makes them stand out is the way they constructed these stories, and brought them all together. These episodes are not just one interview after another. They create a space through interviews, narration, ambient sounds, music and changing environments, that pull listeners into the story, allowing us to paint a picture of the events that are unfolding. This affective power of sound and voice means we can be moved by listening to oral history; this, in turn, affects how we absorb and retain its content, as well as how we judge that content. Moreover, when a host narrates an experience in an

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³⁴ Ira Glass. "487: Harper High School, Part One." *This American Life*. Chicago Public Media, February 15, 2013. https://www.thisamericanlife.org/radio-archives/episode/487/harper-high-school-part-one. Accessed on July 29, 2017.

affecting way (i.e., with palpable emotion), listeners will register the emotion through the prism of their own lived experiences; we can infer that this personalization will confer added impact.³⁵

Aphantasia is the core of my audio documentary. Through it we get to know more about its discovery from Adam Zeman. We get a first-hand personal account of being aphantasic through Tom Ebeyer. All of this is tied together with my narration, guiding the listener through the exploration of aphantasia, piecing together the different stories into one fluid narrative experience, with carefully chosen music to accentuate the moments of reflection.

Accessibility

Podcasts are rooted in radio; it is where they come from, and as a medium of dissemination for oral history, radio has not one but two main benefits: the capacity to convey the oral/aural nature of oral history and the ability to reach a potentially much wider audience than the rather self-selecting field of, for example, readers of books or visitors to museums. The latter aspect is vitally important: you don't need to be literate to absorb oral history on the radio, thus democratizing ideals of the discipline.³⁶

Podcasting takes this integral history of radio and accessibility, and brings it a few steps further. What Netflix has done for television, is exactly what podcasting has done for radio, but years ahead of the Netflix era. We are no longer tied to a specific moment in time when we have to tune in, we can listen to a podcast any time after an

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³⁵ McHugh, Siobhan. "The Affective Power of Sound: Oral History on Radio." *Oral History Review* 39, no. 2, 2012.

³⁶ Ibid.

episode has been released. And I combine my favourite part of the day (listening to a podcast), with my most dreaded, doing the dishes, allowing me to enjoy the latter.

Storytelling through narration

The use of a narrator is not always necessary, but my reason for including my voice stems from interest; I like being a host on stage and "on air" with podcasting. I do not necessarily want to be the center of attention like a talk show radio host, but I do want to help convey the message that is being told, through storytelling.

Using a narrator can be a simple as just hearing a voice at key points to push the story along like you hear with CBC Radio's *Ideas*, ³⁷ or you can have a more active role where you are heard engaging the subjects of your documentary as you find in podcasts like *Reply All*. ³⁸ Here, the hosts continually interject the interview to continue telling the story. I produced something in the middle.

With a podcast like *Reply All*, where there is more than one host, their episodes often have one host sharing and telling the story to the other which allows for a spontaneous reaction. For example, in episode 79, "Boy in Photo," host P.J. Vogt heads out with producer Tim Howard to find out who the boy in a photo was. As they are revealing the story to producer and occasional host Sruthi Pinnamaneni, she is completely unaware of where the story is going to go, and how it will unfold. This style

³⁸ PJ Vogt and Alex Goldman. 2017. "Reply All - Gimlet Media". *Gimlet Media*. https://gimletmedia.com/replyall/. Accessed on August 29, 2017.

³⁷ Paul Kennedy. 2017. "Ideas with Paul Kennedy". CBC Radio. http://www.cbc.ca/radio/ideas. Accessed on August 29, 2017.

³⁹ PJ Vogt and Alex Goldman. 2017. *Boy in Photo,* "Reply All - Gimlet Media". *Gimlet Media*. https://gimletmedia.com/episode/79-boy-in-photo/. Accessed on August 29, 2017.

of documentary storytelling and hosting definitely interests me, but with this particular project in the way in which I presented it, it might not have worked as well because there is so much to unpack, and there will be many, many questions. Which could then possibly derail the entire live show experience. But this is something I could have explored in a controlled studio setting, where I could then edit the spontaneous conversations down, after we were done.

My style of hosting could also be attributed to documentary filmmakers like Louis Theroux and Michael Moore. Theroux produces films and television programs where he is seen throughout the piece, interviewing and engaging his subjects. In his 2003 film, *Louis and the Brothel*,⁴⁰ Theroux explores the world of women who work in one of Nevada's many brothels. Through his direct experience, engaging and interacting with his subjects, he shares their stories. However, he is actively involved in how the story unfolds, his direct presence in the brothel and his interaction with his subjects does have a direct effect their lives. Michael Moore also uses this same technique to confront and interact with his subjects. While the style in which I hosted this podcast is similar, I do not go so far as to participate in the story. I am your guide to the story, and I help unpack the information that needs to be conveyed to the audience. Unlike Theroux and Moore, my involvement does not change the outcome of the story being told.

⁴⁰ Louis and the Brothel. (2003). Directed by L. Theroux. United Kingdom. BBC.

Live Performance and Interaction

In the 1930s, 1940s and 1950s families and people would gather around their radios, excited to hear the next installment of their favourite radio play. ⁴¹ There was an excitement to hear that next episode, and that same excitement has transitioned beautifully into the podcasting world. When *Serial* was first released, it was all I, and most of my friends, could listen to. Each week, we would wait with an impatient anticipation for latest episode delving deeper into the mysterious death of Hae Min-Lee, and the question of whether her ex-boyfriend who was convicted with her murder, Adnan Sayed, was truly innocent, as he claimed he was, or not. While we do not gather together and huddle around the radio, or in this case a computer, to take in the new episode, we do engage in our shared excitement the next day, or online. But, sometimes coming together in a group to experience something as "one" can engage us even more. Cue the live podcast show and recording session.

One of the best things they have ever done on *This American Life* was not on the radio. It was an episode of the show that they did on stage and beamed live into movie theaters.⁴² The *Invisible Made Visible* brought documentary, live to the stage, and to theatres throughout the United States and Canada, incorporating a full range of artistic practices, including dance, music, animation, all weaved through live storytelling. The structure of the show followed the same as their radio show and podcast, but gave it new life by bringing people together in one theatre, and many

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⁴¹ (Owens 2013). "Old-Time Broadcasts for New-Time Podcast." *The English Journal* 102, no. 6 (2013): 66-70. http://www.jstor.org/stable/24484128.

⁴² The Invisible Made Visible, prod. Ira Glass, perf. Mike Birbiglia, Ira Glass, Tig Notaro, David Rakoff, David Sedaris. (Birbiglia, et al. 2012) (Birbiglia, et al. 2012) The Invisible Made Visible, accessed August 16, 2917, http://live.thisamericanlife.org/.

theatres to share and be part of the experience. A key element was an interactive musical performance by the band OK GO, where they developed a mobile app for both iOS and Android enabled phones, which allowed the audience to participate in the performance of the song.

Inspired by this show, and also live storytelling, I wanted to create a similar documentary experience that would allow the audience to not only watch the show, but be a part of it. I also wanted the audience to feel more engaged in the story, and share in the experiences going through the live show. By allowing them to be a part of it, they could have a better understanding of it, and it also allowed for a richer completeness to the experience for me, and the story I was telling. This was not just me sharing a story, it was the audience directly engaging in the process.⁴³

This does change when you just listen to the recording of the live show. You are no longer actively participating the creation of the art, but you are still experiencing what others had help create. This could have been, and still can be, different. In the initial concepts of producing a live show, I wanted to create a mobile app that would allow the audiences both in the space and listening later to be able to participate in the piece, by allowing them to open a mobile app on their phones, and engaging with specific questions, like picturing a horse at the opening.

In the end, identifying intersections between multiple interviews, weaving them with affective auditory elements such as ambient sound and music, so that the final product could unfold as a seamless, cogent, and compelling narrative, created and delivered an accurate representation of the topic in an aesthetically pleasing listening

⁴³ Nato Thompson. 2012. *Living As Form*. Cambridge: MIT Press, pp. 16-33.

experience,⁴⁴ mixed with an interactive element to further engage and include the audience.

⁴⁴ McHugh, Siobhan. "The Affective Power of Sound: Oral History on Radio." *Oral History Review* 39, no. 2, 2012.

Conclusion

When I first discovered aphantasia through Tom, I needed to know more. It fascinated me. Originally this was going to be an episode of a podcast series I was working on. But the more I started to unpack Tom's story, and learn more about aphantasia, I realized this was something much larger. So, we kept digging, and were led down so many paths. In the end, I had recorded over ten hours of interviews, which was edited down to what became a 60 minute or so live show. This 60-minute podcast only touched the surface of aphantasia. There was so much I wanted to include, but just could not. There was not enough time.

Unpacking aphantasia for an audience to understand needs moments of reflection, and bombarding them with too much information would have taken them out of the experience. There is also the inclusion of perception on a much deeper level. Which opens up even more doors and directions this project could evolve. So, where does this leave project? As of now, Tom and I are discussing further ways to explore everything we could not include. That could be another podcast episode, or a miniseries, we still have not decided.

When I started the MFA in Documentary Media, there was a driving force behind me to tell stories. That has not changed. I always believed the documentary work I created needed to have some kind of impact, through exploring something from a different angle, or by telling a story that had not been told. In the end, it ended up being the latter. An interaction with something that inspired me to react and create. That is exactly what happened when Tom told me to picture a horse.

Word count: 10,134

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Appendix A – Letter from Adam Zeman to "Non-Imagers"

I am writing in response to your message about Carl Zimmer's article in Discover on visual imagination. I am the first author of the paper Carl Zimmer's article referred to.

You were one of around 15 people who made contact following this article to report that – in most instances - you had *never* experienced visual imagery (while, of course, the patient we describe, MX, had experienced vivid visual imagery until he lost it abruptly in mid-life).

Although it has been recognised since the 19th century that some people get along very well without having the experience of visual imagery, surprisingly little scientific attention has been paid to this fascinating fact.

If you are willing to help us, my co-authors and I felt that we should take this unexpected opportunity to learn a little more about visual imagery – and its absence.

I am attaching two short questionnaires. I would be very grateful if you could complete and return these electronically.

The first is newly created, and asks a range of questions about matters connected with imagery, for example whether your dreams contain visual imagery. These questions are often raised when imagery is discussed, and we hope that your answers will help to clarify the experience of people who lack imagery.

The second is a widely used 'vividness of visual imagery questionnaire'. We expect you to rate your imagery at the low end of the spectrum – given what you have written – but it would be helpful to quantify your experience using this standard measure.

We have been studying imagery in normal folk to follow up our work with MX. We anticipate putting the data we have gathered from these participants together with what we learn from your answers to write a paper drawing attention to the neglected phenomenon you have described. Looking to the future, as we now have tools to study the working brain in action, it should soon be possible to discover why there is such a wide variation in the vividness of imagery. Your responses will highlight the variation we need to explain.

Any information you provide will be used in an anonymous fashion. Unless you prefer not to be informed, I will keep you in touch with the results of this small survey, and send you a copy of any publication that results.

Many thanks for contribution so far, and for helping with this work.

Best wishes

Adam

Appendix B - Aphantasia: How it Feels to Be Blind in Your Mind by Blake Ross

April 22, 2016

https://www.facebook.com/blake/posts/10156834777480504

Date accessed: December 10, 2016.

I just learned something about you and it is blowing my goddamned mind.

This is not a joke. It is not "blowing my mind" a la BuzzFeed's "8 Things You Won't Believe About Tarantulas." It is, I think, as close to an honest-to-goodness revelation as I will ever live in the flesh.

Here it is: You can visualize things in your mind.

If I tell you to imagine a beach, you can picture the golden sand and turquoise waves. If I ask for a red triangle, your mind gets to drawing. And mom's face? Of course.

You experience this differently, sure. Some of you see a photorealistic beach, others a shadowy cartoon. Some of you can make it up, others only "see" a beach they've visited. Some of you have to work harder to paint the canvas. Some of you can't hang onto the canvas for long. But nearly all of you have a canvas.

I don't. I have never visualized anything in my entire life. I can't "see" my father's face or a bouncing blue ball, my childhood bedroom or the run I went on ten minutes ago. I thought "counting sheep" was a metaphor. I'm 30 years old and I never knew a human could do any of this. And it is blowing my goddamned mind.



If you tell me to imagine a beach, I ruminate on the "concept" of a beach. I know there's sand. I know there's water. I know there's a sun, maybe a lifeguard. I know facts about beaches. I know a beach when I see it, and I can do verbal gymnastics with the word itself.

But I cannot flash to beaches I've visited. I have no visual, audio, emotional or otherwise sensory experience. I have no capacity to create any kind of mental image of a beach, whether I close my eyes or open them, whether I'm reading the word in a book or concentrating on the idea for hours at a time—or whether I'm standing on the beach itself.

And I grew up in Miami.

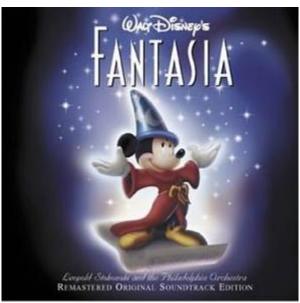
This is how it's always been for me, and this is how I thought it was for you. Then a "Related Article" link on Facebook led me to this bombshell in The New York Times. The piece unearths, with great curiosity, the mystery of a 65 year-old man who lost his ability to form mental images after a surgery.

What do you mean "lost" his ability? I thought. Shouldn't we be amazed he ever <u>had</u> that ability?

Neurologists at the University at Exeter in England showed the man a photo. Who is that? *Tony Blair, of course*. Brain scans showed the visual sectors of his brain lighting up.

Then they removed the photo and asked him to imagine Tony Blair. The man knew characteristics—his eye color, his hair—but he could not "see" the image in his mind's eye. Brain scans showed the visual sectors didn't activate this time. In fMRIs of other men, many of the same sectors activated whether the subjects were looking at a photo or simply imagining one.

The researchers gave the phenomenon a name. They combined the prefix "a," meaning "absence of," and "phantasia," a Greek word you will recognize from childhood:



Aphantasia. The absence of fantasy.

Reading this article was extraterrestrial puberty. I walked in a doe-eyed human; at Tony Blair, the pustules sprouted; by the end, my voice had cracked and I breathed fire.

Because as mystified as the reporter was with his patient, so I was with the reporter. Imagine your phone buzzes with breaking news: WASHINGTON SCIENTISTS DISCOVER TAIL-LESS MAN. *Well then what are you?*

I opened my Facebook chat list and hunted green dots like Pac-Man. Any friend who happened to be online received what must've sounded like a hideous pick-up line at 2 o'clock in the morning:

—If I ask you to imagine a beach, how would you describe what happens in your mind? —Uhh, I imagine a beach. What? —Like, the idea of a beach. Right? —Well, there are waves, sand. Umbrellas. It's a relaxing picture. You okay? —But it's not actually a *picture*? There's no visual component? —Yes there is, in my mind. What the hell are you talking about? —Is it in color? —Yes..... —How often do your thoughts have a visual element? —A thousand times a day? —Oh my God.

I texted friend after friend that night, and together we eloped on journeys of the mind. It is not an easy thing to compare thought processes. It's like trying to teach your dog to sit using nothing but a bowl of strawberries. But, often, it was a hell of a lot of fun.



Even after the Exeter study, I was certain that what we had here was a failure to communicate. You say potato, I say potato. Let me be clear: I know nobody can see fantastical images through their actual eyes. But I was equally sure nobody could "see" them with some fanciful "mind's eye," either. That was just a colorful figure of speech, like "the bee's knees" or "the cat's pajamas."

Or "counting sheep."

But I have now taken this journey with 74 friends and relatives, and I am certain the difference transcends language. Fully 71 of them described—in terms quite similar to one another—the experience of creating a mental image in their mind. (One friend,

<u>Chris Pan</u>, told me he didn't have time to imagine a beach but that he'd do it later. I have never heard a better sign of the times.)



Nearly every friend volunteered the words "picture" or "image" without prompting, a vernacular I would never think to use in describing my own experience. And is this "mental picture" in color? Of course it is—because the beach I visited was in color. But the very foundation of the question does not compute in my brain. It's like asking me if the number seven has any stubble, or if the puppy is on a leash. What puppy?



I found three other people who shared my experience. Two are fellow Facebook engineers, <u>Ben Maurer</u> and <u>Olaoluwa Okelola</u>, both of whom shared some sense of lifelong "otherness" they could never pinpoint. We started a thread to compare our tics

and quirks—it's a lot of "YES!" and "exactly!!" and "wow you too?"—and I felt that transcendent warmth I've only known once before, when a dorky high school outcast in Florida stumbled on a group of California programmers who just seemed to "get him."



It's the feeling of finding your people.



Here are the top 20 questions I've gotten from friends and family.

1. Can you picture my face?

No. But it's not personal.

2. So you don't know what I look like?

I know facts about the characteristics of your face. If you have radiant blue eyes, I may have stored that information. I know the "essence" of your face, but I'm unable to project it visually in my mind because there's no screen.



3. So you don't recognize me when you see me?

I do. Exeter's MRI results suggest that the process of <u>putting a name to a face</u> can be separated from the process of mentally generating a face from a name. In programming parlance, I have a hash table.

4. How about picturing something simpler, like a red triangle, or the table right in front of you?

I can't even understand the question. I can think about the *idea* of a red triangle. But it's blackness behind my eyes. Blackness next to my ears. Blackness in every nook and kindle of my brain.

5. You're just assuming that others can actually SEE things with their eyes. NOBODY can do that, you hypochondriac.

I get it. It's a "mind's eye." I don't have it.

6. Does this apply to other senses?

This is another question that doesn't quite make sense to me. It didn't even occur to me until people kept asking.

I can't read this in Morgan Freeman's voice, nor can I "hear" the theme song to Star Wars in any sort of "mind's ear."

I do have the 'milk voice'—that flat, inner monologue that has no texture or sound, which we use to tell ourselves: "Remember to pick up milk." I can "doo doo doo" in my milk voice and tell myself I'm singing the theme song to Star Wars. However, most of my friends and family describe what they "hear" as music—not as vivid as the real thing, to be sure, and not as many instruments—but "music" nonetheless. I would never describe my experience as such; it's just the flavorless narrator, struggling to beatbox. And I've never had a song "stuck" in my head.



Virtual reality also seems redundant now.

More generally, I have no sensory experience in my mind of any discernible nature. Thinking about a beach doesn't make me feel calm; thinking about a tarantula doesn't give me goosebumps. I can't "recall" the taste of pizza, the feel of velcro, or the smell of Ghirardelli Square. But it's unclear how many other people can. In my surveys, mental imagery and audio were most common, followed by the ability to trigger a feeling in response (the *joie de vivre* of the beach, or spider shivers). Taste, touch, and smell trailed.

7. What is going through your mind all day, if not sights and sounds?

All narration, all the time. An infinite script of milk voice dialogue. When you read a sarcastic essay from me, it is a transcript of this voice.

8. Do you dream?

No, or I don't recall them. I've had a couple dreams but there was no visual or sensory component to them. When I woke up, I just knew a list of "plot points" about things that happened. This is also how I digest fiction.



9. How do you imagine things?

First I think of a noun in my milk voice: cupcake. Then I think of a verb: cough. Finally an adjective: hairy. What if there was a hairy monster that coughs out cupcakes? Now I wonder how he feels about that. Does he wish he was scarier? Is he regulated by the FDA? Does he get to subtract Weight Watchers points whenever he coughs? Are his sneezes savory or sweet? Is the flu delicious?

If I don't like the combination of words I've picked, I keep Mad Libbing until the concept piques my interest.

This has always struck me as an incredibly inefficient way to imagine things, because I can't hold the scene in my mind. I have to keep reminding myself, "the monster is hairy" and "the sneeze-saltines are sitting on a teal counter." But I thought, maybe that's just how it is.

10. How do you masturbate?

Welp, I just learned a lot about how you masturbate.

11. Did you ever have surgery or an injury?

When I was a boy, my camp counselor in North Carolina chased me around the edges of the pool (he would've made a great counselor at Camp Tort-a-Lawsuit). I slipped, hit my head and blacked out. My 10th birthday was spent in the hospital watching O.J. Simpson speed away innocently in a white Ford Bronco. I don't remember if I could visualize before this, but then, I don't remember much in general.

12. How many people have this experience?

It's hard to know. A psychology professor's <u>survey of 2,500 people in 2009</u> suggested it affects 2%, but there haven't been enough rigorous studies. Take an abridged survey in <u>this BBC article</u>. If you think you're affected, email the head of the Exeter research team, <u>Professor Adam Zeman</u>, to join his effort. I've done so as well, and I'm looking forward to getting MRI results and funding future research.

<u>Apparently geneticist Craig Venter is aphantasiac.</u> Also check out Penn (of <u>Penn and Teller</u>) discussing his experience on <u>his podcast</u> (75:15) last year. His experience matches mine perfectly.

13. How do you write fiction if you can't visualize scenes?

It is somewhat amazing to learn that I have given people an experience I myself have never accessed:



I "imagine" scripts conceptually as described earlier. It's easier to write for characters that have already been realized on the screen, especially when so many of them share my dry, sarcastic personality. If you reread the Silicon Valley script, you'll find it's heavy

on ideas (what if a lawyer had a clock that counted money not time? what if Erlich compiled interview questions while stoned?) and light on descriptive language. Same with the Theranos parody.

Overall, I find writing fiction torturous. All writers say this, obviously, but I've come to realize that they usually mean the "writing" part: They can't stop daydreaming long enough to put it on the page. I love the writing and hate the imagining, which is why I churn out 50 dry essays for every nugget of fiction.

14. How do you design product interfaces if you can't visualize them?

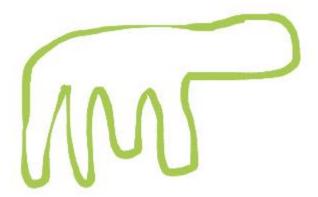
I'm strong at the conceptual aspect: Figure out how a function fits into the overall system; figure out the minimum set of features it requires; strip every other whisker. I'm weak at designing the aesthetics.

15. How do you play the piano?

I can identify notes in sheet music as well as I can identify your face. Once I've played a song enough, my fingers can find the keys without looking as well as yours can find F and J on a laptop. Obviously I don't have perfect pitch, but most people don't.

16. Can you draw?

No. This has been my rendition of a cat/dog/bird/Hugh Jackman/cupcake monster since I was 3:



17. Can you spell?

Yes, very well. But I don't process it like this:



It feels more like muscle memory to me.

18. How do you navigate directions?

Barely, which has been a running joke in my family. I recall directions as a list of facts, like this.

19. How could you go your whole life not knowing that I "see" mental images? How could you go your whole life not knowing that I don't?

20. I don't believe you.

I don't believe you either, frankly. No matter how many asses I inspect, I still can't believe you've all got tails.



Now that I've seen this *Sixth Sense*-style twist ending, friends and I have been "rewatching" the world to spot the hints I missed. So Tony Robbins really does want you to "picture" your six pack to get fired up, <u>Brock</u>? You really *can* visualize a future with your partner, <u>Morin</u>? When you daydreamed in class, <u>Stephen</u>, you really saw that frog in the tuxedo? Wait... THAT'S why it's called "daydreaming"?! He's been dead the whole time.



An ex says I often complained that "it's like my brain just doesn't work this way" while trying to compose fictional scenes, a bizarre framing compared to other admissions that I was simply "bad at baseball" or "not street smart." The dialogue is so on the nose that, if I read it in a script, I'd ding the writer for her assault on subtlety.

And, suddenly, fiction clicks. Paty says I used to worry that "I feel like I'm doing reading wrong." Descriptive language in novels was important to her but impotent to me; I skip it as reflexively as you skip the iTunes Terms of Service. Instead, I scour fiction like an archaeologist: Find the bones.

The slender, olive-skinned man brushed the golden locks out of his hazel eyes. He was so focused on preparing for the assassination that he burned his tongue on the scalding cuppa joe (hazelnut, light cream).

That becomes: There's an assassin.

I hurdle over paragraphs and pages, mowing down novels in one night because—while others make love to the olive-skinned assassin—I'm just fucking his skeleton. Some books are so fleshy they're opaque: Lord of the Rings numbs. But Lord of the Flies gnaws, because I could meditate on the idea of society-gone-wild forever. Animal Farm is awesome. 1984. The splendor of Hogwarts is lost, but the idea of a dementor is brain fuel. And 2 + 2 = 5.

Nobody likes an author who shows off, of course. But friends tell me it is the written imagery—when done well—that delivers the very joy of reading. I can't understand

that, but I finally understand this: You really *are* annoyed with the actor in 50 Shades of Grey. It's really *not* how you pictured him in the book.



Exploring this with friends has been hilarious and maddening and surreal. When I gave the beach test to <u>Brit</u>, she replied: *Umm, have you seen my Facebook cover photo?*



Brit Fisher

I had not.

But above all, strangely, I feel relief. It is vindication in some lifelong battle against an enemy I could never find.

I've always felt an incomprehensible combination of stupid-smart. I missed a single question on the SATs, yet the easiest conceivable question stumps me: What was it like growing up in Miami?

I don't know.

What were some of your favorite experiences at Facebook?

I don't know.

What did you do today?

I don't know. I don't know what I did today.

Answering questions like this requires me to "do mental work," the way you might if you're struggling to recall what happened in the Battle of Trafalgar. If I haven't prepared, I can't begin to answer. But chitchat is the lubricant of everyday life. I learned early that you can't excuse yourself from the party to focus on recalling what you did 2 hours ago.

So I compensate. Ask about Miami and I'll tell you, almost to a syllable:

I didn't love it. It's very hot, the people there aren't ambitious at all. Also everyone is kind of angry, there's like a lot of road rage. It's fun to visit but I basically went as far away as I could for college, ha ha.

Facebook?

It was awesome getting to be there in the early days. I remember I would practically run to work in the mornings because I was so excited to share ideas with the team. There's really no better feeling than seeing someone in a coffee shop using your work. These lines are practiced. They are composites of facts I know and things I've read. I perform them out of body, with the same spiritual deadness that you might recount the Battle of Trafalgar.

And if you ask about my day, there's a good chance that—having had no time to prepare—I'll lie to you.

It is hard not to feel like a sociopath when you're lying about how you spent your Monday and you don't even know why. And there is a sadness, an unflagging detachment that comes from forgetting your own existence. My college girlfriend passed away. Now I cannot "see" So-Youn's face or any of the times we shared together.

I have, in fact, no memories of college.

I once proposed to Paty that, since we were visiting my brother in DC anyway, let's train over to the Big Apple and see Les Misérables. She said, we did that last year—for my birthday.

Often I ask my oldest friend to tell me about my childhood. Stephen and I joke that we're the couple in *The Notebook*, but there's an undercurrent of: Am I an idiot? It is hard not to feel like a sociopath when you're lying about how you spent your Monday and you don't even know why.

I've always chalked this up to having "bad experiential memory," a notion I pulled out of thin air because "bad memory" doesn't fit: I can recite the full to-do list of software I'm building. On a childhood IQ test, my best performances were on Coding and Digit Span, both memory-driven. Given an increasingly long string of random numbers, I hit the test ceiling by repeating and then reversing 20 digits from memory on the fly. My three worst performances were on Picture Completion, Picture Arrangement, and Object Assembly. I couldn't put the damn images in order to save my life.

Behavioral Observations: Blake is a nice-looking 12-year old boy, with black hair & brown eyes & freckles, who was highly motivated to do well and was self-depricating whenever he thought his response was not correct (e.g., on Picture Completion if could not see what was missing would say "I feel bad" or "Is it really obvious?").

My IQ test, the Wechsler-III. It is unclear if we can trust an IQ examiner who misspells "deprecated." Also, is it normal for them to comment on a little boy's looks? Mom, I feel bad.

Perhaps none of this is aphantasia. But when I ask a friend *how* he how-was-your-days, he gives me a tour of the visualizations in his mind. The spaghetti bolognese; the bike ride through the marsh; the argument with the boss, and the boss's shit-eating grin, and gosh how I'd love to punch him in the mouth, and can't you just see it now? He says that looking back on his life is like paging through a Google Image search sorted by "most engaging." He tells me that when he's on the road, and loneliness knocks, and the damn Doubletree bed is a little more wooden than usual, he replays the time they tried to make sushi together—but the rice kept falling apart!—and we couldn't stop laughing!—and did you know it burns when sake spews out your nose?—and that's when she feels closer.

I wonder if it's why I have such an easy time letting go of people.

Is It Really Obvious?

I learned what it means to count sheep from a friend who was also teaching his daughter.

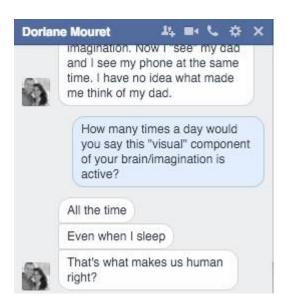
That is ethereal. Musical. Hysterical. Eye-rollable rom-com mix-up stretched past the point of plausible. Oh but when you said—oh I thought you meant that—Ohhhh! Haha! How could you not know? What did you do when mom told you to tend the flock at midnight?

Well, here's a little *Sixth Sense* ending of your own: The final member of Aphantasiacs Anonymous turned out to be my mother.

Imagine that.

Some people don't find out until they're 50. Some never do. How close did I come to asking the right question all these years, only to stumble on a Facebook article? Brand new writer has no imagination! Oculus on the eyes, blind in the mind! The clickbait headlines write themselves, and maybe next time your jaded ass should bite. You never know.

Before I told her what was going on, **Doriane** offered this:



I think what makes us human is that we know we're the galactic punchline, but we can still laugh at the setup. The cosmos got me good on this one. How beautiful that such electrical epiphany is not just the province of the child. And were the bee's knees real, too? And have the cats worn pajamas all along? I don't *think* so.

But if I see it, I'll be sure to tell my people. 🤒

Blake Ross is a writer and programmer. He was a Director of Product at Facebook, and the cofounder of Firefox. Read more of his writing on <u>Facebook</u>, <u>Medium</u> and <u>Twitter</u>.

Thanks to all my friends who tripped out with me: Jess, Marshall, Paty, Tom, Naomi, Samuel, Skye, Henry, Jon, Taner, Brandon, Mike, Lizzy, Dave, Christine, Bobby, Maggie, Olaoluwa, Tessa, Mandalay, Noel, Mia, Catharine, Allison, Liz, Becca, Ben, Ben, Mark, Lucinda, Ashley, Stephen, Brittany, Kathy, Jeff, Andrea, Lauren, Pedram, Suedy, Nicholas, Doriane, The Facebook Tagging Limit, Caitlin, Danny, Courtney, Lana, Morin, Tom, Ankur, Isaac, Nicolet, Brendan, Jennifer, Pola, Allie, the other Marks, Anjali, Elisa, Nicole, Elliot, Jamie, Tanja, Viviana, the Ferriers, Andrew, Kalani, Erin, Max, Peter, Stephanie, Georgia, Charlotte, Tiffany, Kathleen, Will, Novati, Alex, Joel, Vanessa, Sabina, the Scotts, Jessica, Kate, Allison, Martina Stipan (for the great artwork), and my family.

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Password: silence