The Story of Illness

A study of the narrative writings of the ill

By,

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Abstract

My thesis is concerned with the rising genre of illness narratives over the last couple decades. Its goal is to analyze common aspects of these autobiographies that are unique to the genre and explore how they may cause us to think differently about the experience of illness. I am analyzing two narratives that are very different in style, tone, and content: Jean-Dominique Bauby’s *The Diving Bell and the Butterfly* and Lucy Grealy’s *Autobiography of a Face*.

The first chapter looks at recovery in the stories. It does not look at the physical recovery of the narrators, but instead at their struggles to develop content lifestyles. For Bauby, this involves redeveloping relationships and redefining daily tasks as he is forced to live with Locked-In-Syndrome, a condition in which nearly his whole body is paralyzed because of a stroke. For Grealy, recovery involves learning to live with her deformed face since a third of it was lost to surgery resulting from jaw cancer. The two narratives achieve that recovery in very different ways through their writings, but both narratives raise questions about how exactly a person can achieve recovery. Both Bauby and Grealy do not recover under typical terms; they recover by converting their perspectives on the world. Bauby’s narrative shifts in tense and in time to reveal his recovery while Grealy’s writing changes in its emotional tone as the story progresses.

The second chapter will deal with another common issue in illness writing: the loss of authority. I examine a patient’s general loss of voice (figuratively) and opinion because of the medical system. There is a short discussion about theories regarding how the medical system functions to control authority. However, both Bauby’s and Grealy’s losses of authority are exacerbated by Bauby’s inability to move or speak and by Grealy’s immaturity (the book spans the period between her diagnosis as a nine-year-old to her late-teen years). In order to regain that lost authority and lost control, Bauby uses his narrative to prove his worth and value in the world while Grealy takes a different approach. Her narrator needs to prove her maturity, and she does so by accepting guilt for her childishness during the illness and by giving the narrator an extremely reflective and often self-loathing tone when describing her experiences.

The third chapter uses the first two chapters’ topics to explore the concept of audience in these illness narratives. What types of audiences read these books? Doctors also benefit from the books because so much detail about patient mentality is revealed in the writing. Fellow patients can benefit from these memoirs by finding strength in them and by feeling empathy with the writers. However, my research demonstrates that illness autobiographies are most strongly written for the average person—the unspecified reader. The authors hope to reach out to readers who may have been previously oblivious to the authors’ stories, thus allowing the readers to develop an understanding and an emotional connection with the writers.

Illness narratives are conversations. Readers sympathize with an author’s struggle and often are able to relate to some aspects of the story or at least take some sort of lesson away from it to apply to their own lives. Some illness narratives, like the two analyzed in this project, discuss very specific and very rare conditions. Yet, the stories are immensely popular. This is because the nature of the illness is not as significant in these narratives as the progression of the protagonist’s struggle to fully recover from such misfortune, and how the manner in which the protagonist recovers may challenge the typical definition of health.
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Introduction

What are Illness Narratives and why do they Matter?

"Meaning is inescapable: that is to say, illness always has meaning. The experience when ill need not be self-defeating; it can be—even if it often isn’t—an occasion for growth, a point of departure for something deeper and finer, a model of and for what is good."

Arthur Kleinman (144)

As a pre-medical student who hopes one day to become doctor and also as someone with a devoted interest in literature and language, the genre of illness narrative has always been interesting to me. Illness narratives reveal how illness is often complex, that a unique experience exists for each individual who goes through any health matter whether it be a terrible disease like cancer or the ordeal of pregnancy. More so, the genre connects to a larger concept of empowering patients, which is a growing concern in the field of medicine. Issues in medicine that most interest me are those that extend beyond the physical symptoms into more abstract topics such as emotional recovery and a sense of agency; these are found within illness narratives. This thesis will look at how two specific authors’ styles, techniques, and words reveal the significant events of their experiences, approaching illness narratives from a literary perspective and not a medical perspective. The illness experiences focused on are Jean-Dominique Bauby’s in his book, The Diving Bell and the Butterfly, and Lucy Grealy’s in hers, Autobiography of a Face.¹

Arthur Kleinman is generally credited as with developing the term “illness narrative.” Evident in my epigraph is Kleinman’s belief that a story of illness is filled with meaning, and, that a story and an experience exist beyond the physical conditions of an illness. I define an illness narrative as any autobiography told by a person suffering from a medical ailment or who

¹ From now on these texts will be referred to as DBB (The Diving Bell and the Butterfly) and AF (Autobiography of a Face)
suffered from one in the past. More than just a list of medical terms, an illness narrative incorporates the author’s lifestyle, friends, family, and emotional turmoil which are all affected or caused by the affliction. These stories are autobiographies that demonstrate how illness has altered the autobiographer’s life.

Since illness narratives can be determined to be a sub-genre of autobiography and narrative writing, I will examine theories on these broader genres will be examined within this thesis. They are autobiographies in the sense that the author is writing about his or her own experience and they have elements of narrative as well. But as the two books in this thesis will demonstrate, there is an interesting distinction between author and narrator for illness narratives. Also, the two authors that are the focus of my thesis deal with traumatic events related to their illnesses. I will, therefore, be discussing trauma theory as well. Components of autobiographical, narrative, and trauma writing can be found within these texts, and thus these writings will be discussed within my conclusions about illness writing.

The first text, DBB, is written by Jean-Dominique Bauby who suffers from a cerebrovascular condition called Locked-In-Syndrome (LIS). After having a stroke at the age of 43, his body is paralyzed from head to toe; Bauby can only make minor movements in his mouth and blink his left eye. Through blinking his left eyelid, he was able to communicate with a speech therapist, a process that allowed to him to write this memoir. It is also important to note that before suffering the stroke, Bauby was the editor for Elle Magazine, a very popular international fashion magazine, headquartered in France. This is significant because Bauby’s book shows the author struggling to accept his sudden loss of power and authority in addition to his loss of movement. His world of celebrities, fame, money, and power is reduced to being

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2 Illness narratives will also be referenced as ‘pathographies’ throughout this paper, a term with a broader definition than ‘illness narratives’ but synonymous in its usage here.
moticnless in a hospital bed for the rest of his life (except for occasional "walks" in his wheelchair). Given the severity of his condition, it’s remarkable that the book is written without self-pity and with a strong sense of confidence; Bauby rarely allows his readers to see his weaknesses. I want to remind my reader here, because one has to remind oneself while reading the text, that the emotion and passion in his writing is all being communicated through a blinking eyelid and written by another hand. As the short, quick-paced chapters roll onward without any chronological order, the reader almost forgets that the man writing this book is in fact completely paralyzed. The book does not seem to even have the typical format of beginning, middle, and end.

One of the earliest references—and, probably, the earliest literary reference—of Locked-In-Syndrome is in Alexander Dumas’ *The Count of Monte Cristo*. Monsieur Noirtier de Villefort, a father of one of Dantés’ enemies, lives with locked-in-syndrome. Like Bauby, he can only communicate through blinking, and he is described in the book as inhabiting a “miserable body which seemed fit for nothing but the grave” (Dumas 416). Interestingly, Bauby mentions Dumas’ book in *DBB*, and mentions that he had been planning on writing a modern version of it before his stroke (*DBB* 47). With his characteristic humor, Bauby alludes to his belief that his stroke was a “punishment” from “the gods of literature” who did not want him to “tamper with masterpieces” (48). Perhaps, like Monte Cristo, Bauby is seeking vengeance against feeling ‘imprisoned.’ His remarks give the impression that his book symbolizes a revenge against “the gods of literature” or against anyone who doubts his abilities. Except, instead of being Edmond Dantés, Bauby is seeking revenge in the form of Monsieur Noirtier. In a way, this book may be his modernized version of the famous Dumas tale.
Lucy Grealy, on the other hand, writes about a vastly different illness and writes about it in a vastly different way. She was diagnosed with Ewing’s Sarcoma, a form of jaw cancer, when she was nine years old. The cancer was removed when she was ten years old, and most of her narrative covers the decade afterwards as she deals with chemotherapy, reconstructive surgeries, and, most importantly, the difficulty of being a teenager with a facial deformity. After the events that take place in the narrative, Grealy went on to college and studied Creative Writing.

While Bauby’s narrative is more optimistic and warm-hearted, Grealy’s is reflective and self-deprecating. She admits to her faults and is more revealing about the tragedy associated with such a severe illness. Grealy also, unlike Bauby, is distanced from her character, creating a distinct split between her and her childhood self. Therefore, I will refer to ‘Grealy’ as the author and to ‘Lucy’ as the character throughout this thesis when referencing AF. Also, her book is more traditional in its longer chapters, character development, and format.

Although there are many illness narratives worthy of analysis, I chose these two texts because they represent very different types of pathographical writing. The tone and style of the narratives are extremely different: Bauby’s narrative is more optimistic and it takes place almost exclusively in a hospital over the course of three months, whereas Grealy’s more solemn narrative follows her growth from a child to an adolescent to an adult over the course of nearly thirteen years. Other than the tone and style of the writings, the two memoirs differ in content as well. The characters differ in gender and in age. Bauby is a wealthy father while Lucy’s character is an impoverished child. Bauby’s condition is a permanent physical disability while Lucy is technically ‘cured’ of her cancer. All of this gives me the ability to analyze two distinct stories, which causes the thesis to develop a wider perspective on pathographies as a whole.

\(^3\) She is cured since all of the cancer has been removed but, as chapter one in this thesis will demonstrate, her full recovery is more complex than simply the removal of the cancer.
Through different styles and formats, both *DBB* and *AF* are able to answer important questions for us about illness and about this genre of literature. What do these writings reveal about the experience of struggling to overcome illness? What is the focus of their struggles? And, at what point can a patient like Bauby, whose illness is so permanent, or a patient like Grealy, whose illness affects her for so long, feel that they have overcome illness? Only through autobiographical writing, through the patients speaking out themselves, can we best analyze and understand their processes of recovery. Both books do not focus on their illnesses (cancer and paralysis) as much as their lifestyles, drawing the attention and the concern away from what we typically think of when we think of “illness.” The problems in these narratives revolve more around living with illness rather than overcoming illness.

The modes of recovery for these two stories do not fit the typical conception of improving health. The first chapter of this thesis demonstrates how these two narratives define their individual recoveries using distinctive methods and through incorporating that recovery into the language of the texts. Both Bauby and Grealy challenge what classifies health and recovery both within the illness narrative genre and within society. For both, recovery is a form of conversion, learning to manage the consequences of illness rather than ridding themselves of the consequences of illness. The pre-illness perspective on society must be altered to fit a new lifestyle.

Chapter two shows how agency and voice come up in the two stories. Illness, as will be shown, is naturally accompanied by a loss of control. An important aspect of Bauby’s and Crealy’s recoveries is reclaiming a sense of agency in the world. The chapter will look at medical theory and at the relationship between the ill and non-ill. It will explore why illness and losses of authority so often coincide. Then, the chapter will point out instances where this
happens most within these two texts and what these instances teach us about the authors and about overcoming illness. The question of voice connects to the broader concerns of the narrative genre as well. By looking at the specific ways that voice comes up in illness narratives, we can then think differently about how voice is an issue in all narrative writing. When the narrator itself is trying to display agency—in this case as a form of recovery—it causes the reader to look at the entire narrative in a different way.

The last chapter will turn away from the authors and analyze the audiences of illness narratives. Fellow patients and patients’ family members can benefit from these memoirs by finding strength in them and by feeling empathy with the writers. Healthcare professionals also benefit from the books because so much detail about patient mentality is revealed in the writing. However, the most interesting audience is the reader who does not fall under either of the previously mentioned categories. Why does the average, unspecified reader buy an illness narrative? The chapter will analyze all three mentioned perspectives that are taken when reading an illness narrative and will also try to answer this larger question, exploring the idea that illness narratives open a door about suffering and the human condition that is otherwise shut for unspecified readers.

In seeing how these two vastly different illness narratives define their recovery, their reclaiming of authority, and how they address their audiences, we can better understand why Kleinman says that “illness always has meaning.” These narratives simultaneously provide insight into the methods and purposes of narrative writing as well as insight into the experience of illness. The moments of recovery and of reclaiming voice should answer questions about how illness is more than simply a set of symptoms, but rather an experience that requires more analysis than a quick medical examination.
Chapter 1

Issues of Recovery within the Narratives

Chapter Introduction

An essential element of illness narratives is recovery. All authors of these autobiographies by definition are physically recovering from their illnesses. But that is not the type of recovery that is the issue in this chapter. I am focusing on the recovery of the authors’ lifestyles, on the ability of each author to overcome certain limitations associated with the illness. I am not concerned with Grealy’s or Bauby’s physical health as much as I am with their emotional health and the narrative strategies that each text employs to construct its particular definition of health. I argue that these illness stories challenge the socially assumed characterizations of both health and recovery. For Grealy and for Bauby, achieving ‘recovery,’ or being ‘healthy,’ is not what you might expect.

Recovery is not merely as a piece of the storyline in these two stories but is presented in the language and the style of the works. Because the two narratives are very different in style, tone, and content, the recovery comes across in different ways. In order to even write *DBB*, Bauby must have accepted his illness beforehand. The recovery in his narrative comes across through changes in tense and in person that signal this acceptance of his condition, as well as through narratives changes that show his ability to connect his life before the accident with his current life. Grealy sets up the narrative so the reader witnesses the path that Lucy must take to reach this acceptance. She shows Lucy’s difficulty with interacting with society. Lucy goes through many stages of ignorance, self-blame, and doubt before being able to live comfortably regardless of her looks.
Important moments in *DBB* are where Bauby learns new limits, where he takes the reader along with him on imaginative journeys, and where the reader witnesses the progression of relationships (both new ones and old ones). These aspects of Bauby’s recovery are illuminated by the narrative’s shifting tenses, detailed passages about his fantasies and dreams, and the narrator’s altering perceptions on his social life. They are important because it is at these moments that Bauby is framing his illness-inhabited world. His recovery, as it turns out, is not focused on anything physical but aspects of life that are intangible such as perspective, dreams, and relationships.

Grealy’s recovery, on the other hand, revolves around her autobiographical character’s struggle with developing an identity while having a deformed face. The title of the book, *Autobiography of a Face*, proves the thematic significance of Lucy’s face.¹ The cancer, which Grealy covers quickly in the first few chapters and then rarely brings up again, is neither the focus of the narrative nor the main element of recovery. Rather, the focus is Lucy’s face and her accompanied identity struggle. The difficulty of growing up in Lucy’s situation is revealed by her insecurity, and thus, this chapter looks at Lucy’s greatest moments of insecurity and tracks her eventual self-confidence. She, too, like Bauby, is not focused on the physical illness as much as the emotional after-effects.

A common definition of recovery assumes that because a person was healthy before illness, the most likely manner of recovery is returning to that previous state of health. Many critics agree that narrative writing can be instrumental in a person’s recovery, but there seems to be an assumption about what is being instrumented. Arthur Frank, a contemporary sociologist who focuses on illness narratives, explores the ability of storytelling to repair an ill person’s

¹ Recall from the introduction that the author of *AF* will be referred to as Grealy while the protagonist of the story will be referred to as Lucy to better create a distinction between the writer and the character.
damaged way of life. Frank describes: “The act of telling is a dual reaffirmation. Relationships with others are reaffirmed, and the self is reaffirmed” (Frank 56). Frank explains that writing about one’s story helps the writer to retrieve a healthy lifestyle, and that this retrieving is an essential part of recovery. He describes the sick person finding certainty, comfort, and change to achieve such reaffirmations. Moments of restructuring are discussed in this chapter both in relation to AF and DBB, but the idea of reaffirmation is not fitting for these two texts.

When it comes to Bauby’s and Grealy’s stories, Frank’s analysis is too narrow in terms of recovery. DBB and AF each have a unique difference from the typical illness narrative: her youth and his permanent condition. Frank does not acknowledge unique storytellers like Grealy whose illness strikes them when they are very young. His argument that one must “reaffirm” the self through storytelling does not pertain to a girl who experienced her life-changing illness at age nine. Grealy spends very little time in her story describing her “old self,” as Frank puts it, because there isn’t an old self to talk about (68). She was too young to have developed any concrete identity that warrants reaffirmation. She, unlike the examples in Frank’s argument, asserts and discovers her self and her relationships for the first time with the traumatic events of her illness already affecting her. Therefore, she must discover herself in order to recover.

Frank’s analysis also does not consider the possibility that recovery might not involve a return to the past. In Bauby’s situation, there is virtually no hope for a full, physical recovery. He does not intend to reaffirm his lifestyle or return to his old lifestyle. Instead, he must create a whole new one. Bauby’s recovery is not a renewal but a completely new development. To Frank’s credit, he does address this topic briefly in the same chapter, citing Reynold Price’s experience with illness and Price’s advice to other ill people that “A new body calls for a new self” (68). However, Frank doubts Price’s ability to truly develop a new self, and instead focuses
on the idea of a “new self” as a comforting placebo to help someone cope with a new body. This ambiguity over the definition of recovery is an important focus of my analysis. I will argue that the characters in these two narratives do achieve a form of recovery even though it may not fit Frank’s—or, perhaps, society’s—typical definition of regaining health.

Frank’s words also reveal how illness narratives can speak more broadly to the genre of narrative. While Frank is focusing on ill authors in his analysis, “the act of telling” applies to any personal narrative. All telling, all forms of narrative, are a restructuring of the past, even sometimes a reordering of events. To write is to take events that happened in life and adapting them into coherent words, placed in a carefully determined order. Bauby’s and Grealy’s narratives will be the focus of this chapter and of this entire thesis, but it is important to keep in mind that the general aspects of their narrative can be connected to autobiographies and memoirs that are not necessarily written by the ill. In understanding that greater connection, the arguments from this thesis can possibly be applied to other narrative writings.

I need to digress shortly in order to address the issue of ‘self.’ This term comes up in Frank and also comes up in this chapter when referring to recovery. I mirror Frank’s use of the word, “self,” which he uses to refer to a discovery of identity and personhood. Coinciding with Bauby’s and Grealy’s structuring of their lifestyles with illness is a formation of an identity. I do not use the concepts of recovery and of assertion of self interchangeably, but they are very tightly connected in this project.

The confusion for the authors in forming identities, along with the physical results of their illnesses, is somewhat traumatic for the two storytellers being examined here. Both Bauby’s and Grealy’s work incorporates aspects of writing that reflect the work of traumatized victims. In defining trauma, Judith Herman, a professor of psychiatry and a trauma theorist, writes,
“Traumatic events overwhelm the ordinary systems of care that give people a sense of control, connection, and meaning” (33). The confusion, doubt, and pain that Grealy experiences because of her appearance fit this definition. Bauby’s loss of a sense of control and meaning because his new life is isolated to a hospital bed also fits this definition. In fitting the definition of trauma, we can see how these stories incorporate typical modes of trauma recovery. Trauma recovery, then, becomes an important part of both Grealy’s and Bauby’s unique portrayals of what define recovery for patients.

Herman lays out three stages of recovery from trauma, each of which ties into at least one of these two texts at some point. The first stage involves recognizing the problems, being able to accept one’s situation. The second stage calls for “remembrance and mourning” (Herman 155). Herman explains this stage as necessarily incorporating the individual retelling the traumatic events, further stating: “This work of reconstruction actually transforms the traumatic memory” (175). The issue of “reconstructing” the traumatic experience into some form—in this case, an illness narrative—is very applicable to both Bauby’s and Grealy’s writings and to the illness narrative genre in general.² The third and final stage is “reconnection with ordinary life,” integrating the trauma into the traumatized person’s life (Herman 155). This stage applies most strongly to the methods of recovery in these two narratives as the protagonists strive to manage their lives with the trauma. Herman’s total perception of the process of trauma recovery is a large aspect of Bauby’s and Grealy’s overall recoveries since they are traumatized writers. As mentioned before, this overall recovery is different than what Frank assumes to be a typical definition of recovery—returning as much as possible to a previous state of health.

²This analysis Herman’s second stage and how it connects to illness writing is shared by Arne Hunsaker Hawkins in her article “Writing About Illness: Therapy? Or Testimony?” Page 120.
Instead of returning to a previous state of health, Grealy and Bauby recover incorporating forms of conversion. In fact, both narratives borrow elements from the conversion narrative genre. In reconnecting with ordinary life, the two characters must alter their perspectives on life and on what defines recovery for them. Peter Stromberg, in his study of the conversion narrative, defines conversion storytellers, “Those who tell conversion stories generally base those stories in part around the claim that their conversion experiences have changed them in a fundamental way” (Stromberg xi). While the genre typically involves a conversion of faith and religiousness, \textit{AF} and \textit{DBB} do apply the elements of change and “self-transformation” that Stromberg discusses (xi). The main struggle to recovery for both Bauby and Lucy is the ability to change perspective. Bauby’s narrative shows the reader his conversion into a non-physical perspective on life that suits his condition. Grealy’s narrative shows the reader the experience of Lucy’s conversion into a healthy self-perception. While I would not go too far as to label both of these stories conversion narratives, they do resemble broad and generic features of that genre.

Also similar to conversion narratives, both Bauby and Grealy are writing with conflicting impulses. As a conversion-narrative author must simultaneously show his or her previous transgressions and his newfound faith, Bauby and Grealy must write memoirs about illness while simultaneously exuding health. They must reveal the severity of their illnesses at the same time that they are trying to appear triumphant over those illnesses.

The unique situation of Bauby and Grealy is that both of these authors are forming an entirely new self and new way of life in their recoveries. For the two characters in these stories, recovery is measured by their self-transformations; it is an intangible recovery. Therefore, it seems that these two texts do not fit the standard accounts of illness narratives because these two authors never physically recover (fully) and never achieve the standard mode of health. Rather,
their concepts of health are unique; they challenge the way that we think of illness and recovery in general. Illness narratives show that the terms of recovery depend on the illness itself and on the individual’s life, relationships, personality, and behavior.

For Bauby, this recovery comes out in moments of acceptance and in his ability to mentally overcome the tragic realities and boundaries of his condition. For Grealy, this recovery is a matter of her self-perception and her self-confidence. Grealy walks the reader through Lucy’s life and shows the progression of her attitude towards her face as she finally recovers in her ability to distance her self from her body. I will first analyze the theme of recovery in *DBB* and then show how the theme reveals itself in *AF*.

**Bauby’s Recovery**

Before restructuring his lifestyle, Bauby must first accept the consequences of his condition, and he does so by switching from third to first person and by switching tenses. On the second page of the narrative, Bauby immediately tells the reader of the severity of his condition, but refers to himself in the third person: “Paralyzed from head to toe, the patient, his mind intact, is imprisoned inside his own body, unable to speak or move” (*DBB* 4). The passage is very matter-of-fact. The tone is straightforward, listing the symptoms of his condition. The tone is lifeless and emotionless as if he has no connection with “the patient” being talked about.³ More importantly, the passage is told in the third person, even though the reader clearly understands that the narrator himself is suffering. Early in the book, during this passage specifically, the writing shows Bauby disconnected with his body. The narrative speaks about “the [typical] patient” rather than self-identifying himself as the patient. The use of third person here allows

³ This tone, however, shifts as the narrative progresses as Bauby adds more emotion and opinion into the narrative. Introducing his opinions into the story, which connects with the issues of authority and control, will be discussed in Chapter 2 of this paper.
Bauby to distance himself from his condition. Presumably, his body’s inability “to speak or move” reflects a deeper questioning of identity and self, making Bauby wonder about the existence of his personhood. The narrative thus shows the reader that Bauby struggles with looking at his condition and incorporating it into his identity. I will discuss how the narrative shifts from the implications of this passage to directly reveal Bauby’s acceptance of his condition and, later in this chapter, his assertion of self through reconnecting old relationships.

Moments of optimism, hopes of a full recovery, are written in past tense. When the nurses bring him a wheelchair for the first time, Bauby writes,

I thought it meant that I was being ejected to make room for a new patient…I still could not imagine any connection between a wheelchair and me…I clung to the certainty, based on bits and pieces I had overheard, that I would very quickly recover movement and speech” (7).

The reader of the narrative, however, knows that this wheelchair is for Bauby. And the reader knows that he will not recover full movement or the ability to speak. The reader knows these truths because Bauby already told us about the situation of his condition on page 4. More so, Bauby uses past tense frequently in this passage with the words “thought”, “could not”, and “clung.” His moments of denial here are written in past tense, but it is that use of past tense that shows that he is currently in a state of acceptance. By putting his moments of denial in the past and his moments of understanding in the present, the reader understands his acceptance and is able to go along with it. The reader does not go through the rest of the narrative clinging to that same hope. Rather, he or she must accept the permanence of Bauby’s state along with Bauby himself, and the language’s use of past tense causes the reader and the protagonist to share the same mindset, a mindset that acknowledges the severity of his situation.
Fittingly, the moments of acceptance in the narrative are written in present tense and in first person to represent the realism of his situation. In the chapter following the one described above, Bauby discusses his greatest chances at physical recovery. The narrative reads: “It is in my respiratory passages that I can hope for improvement...I can hope to eat more normally: that is, without the help of a gastric tube” (12). He is not clinging to the possibilities that he will walk again, speak perfectly, or regain his old life back. Rather, he understands the facts of the situation, and his understanding is conveyed through the switch to present tense. Further along on the same page, “even before first light, I am already practicing sliding my tongue toward the rear of his palate,” because eating “more normally” is currently his most realistic hope (12).

Once again, Bauby uses present tense and first person speech. The present-tense recognition of the permanence of his illness, along with the placement of these passages in the earliest parts of the narrative, allows the story to plunge forward without hesitation into its journey towards revealing the restructuring of his lifestyle. This is key to the narrative’s progress towards revealing his conversion. As readers, we get a glimpse of Bauby’s struggle to reaching the point where he can look at himself and recognize the permanence of Locked-In-Syndrome. Now, with that recognition, the narrative can move forward into showing how Bauby must now convert his lifestyle and his perspective on happiness to suit Locked-In-Syndrome.

Recalling Judith Herman’s first stage of trauma recovery, Bauby’s moments of acceptance strongly resemble Herman’s stage of recognition. Thus, his recovery does indeed incorporate elements of trauma recovery. If these moments of acceptance were in third person, they would be incredible because Herman suggests that this recognition must be internal. If these moments of acceptance were in past tense, the narrative would give the impression that Bauby is writing this book at a time where such limitations and physical disabilities no longer affect him.
Only through present tense and first person can the narrative best display acceptance because it demonstrates that Bauby understands his situation and understands that it is happening right now (and likely, forever).

Another example of shifting tenses occurs in a chapter where Bauby explains how he finds joy in eating his daily dosage of nutritional, tasteless fluids. He turns this boring intake of nourishment into a “banquet.” It reads: “Once, I was a master at recycling leftovers. Now I cultivate the art of simmering memories” (36). There are two noteworthy aspects of this passage. The first important part is the quick shift from past tense to present tense. “Recycling leftovers” is an activity of the past and it is not something Bauby expects to ever be able to do again. In the present, he can only continue to “cultivate” his memories of smell and taste. Once again, this shift in tense signals acknowledgment of his situation. Second, Bauby is making the present more desirable. The idea of “recycling leftovers” sounds unpleasant and boring, while “cultivating” is a word that seems more exciting and pleasurable. Here is an example of where his acceptance connects to his recovery, because, beyond simply understanding his situation, Bauby is making it appear preferable to the past; he is searching for an upside to his condition in an optimistic tone. In addition to all of this, the narrative is quickly shifting between the past and the present. I will address this technique later in the chapter.

Through accepting the slim hope for change in the future, Bauby is able to reconcile the present. Shlomith Rimmon-Kenan, a Professor of Comparative Literature at Hebrew University and a researcher on narratives in various disciplines, notices that “most illness narratives…tend, with different degrees of self-consciousness, to retell, restructure past memories and future expectations in a way that would cohere with the present, bridging the gap by creating a new kind of continuity” (13). Bauby’s recovery can be understood to be shaped around a renewed
sense of continuity and consistency in his life. For him, the gap is his physicality. The past involves a life of activity and movement. The present is a life of vulnerability and immobility. Also, this consistency comes from restructuring future expectations, which Bauby does in these opening chapters by using past tense to effectively rid his mind of any "grandiose plans" (*DBB* 11). In refining his future expectations of regaining that mobility, he can better bridge the gap between the present and the future.

Regarding bridging the gap between the past and the present, Bauby does not follow Rimmon-Kenan's analysis of "restructuring past memories" to make the present more coherent like he does with restructuring future expectations. Rather, he blends moments of the past together with the present, making the two times in his life indistinguishable. Rimmon-Kenan explains too that illness narratives undergo this phenomenon, saying that the narratives "redefine the present in terms of the past" (17). Notable moments of recovery in *DBB* are conveyed to the reader through referencing the past in order to manipulate the present, moments which will be analyzed in the following paragraphs. Concurrently, the language of the text shifts in and out of memories. Thus, as Bauby (the patient) blends together his past life with his new life, Bauby (the writer) uses the shifting in and out of memories to blend the past and the present for the reader as well. In constantly referencing the past, the narrative makes the "gap" that Rimmon-Kenan described murky. It is hard for the reader to determine what is past and what is present.

For example, in his new life, which is restrained to a hospital bed, Bauby is dressed in only hospital gowns. Bauby complains, "It was a nightmare to put them on. Or rather to watch the clothes manipulated...over these uncooperative deadweight limbs, which serve me only as a source of pain" (*DBB* 8). Putting on clothes has become a source of misery for him in his new life. He reaches an agreeable conclusion by wearing his old clothes. "I see in the clothing a
symbol of continuing life. And proof that I still want to be myself’ (17). In the story, the clothes allow Bauby to maintain a sense of self and personhood because they provide a sense of continuity between his past life and his present life.

However, this continuity is not merely a part of the storyline; it is in the language itself. Before the previously discussed sentence, on the same page, Bauby talks about his baths in the hospital and how they are sometimes a “guilty pleasure” and sometimes “unbearably sad” (17). It then continues, “The delectable moment when I sink into the tub is quickly followed by nostalgia for the protracted immersion that was the joy of my previous life. Armed with a cup of tea or a Scotch, a good book or a pile of newspaper, I would soak for hours, maneuvering the taps with my toes” (17). The narrative, here, shifts in and out of the past. Linguistically, the sentence beginning with “Armed with a cup” seems at first to refer to his current bath, but can also be referring to the one in his “previous life.” It is not until Bauby tells us that he “would soak” and that he is “maneuvering the taps with my toes” that the reader is certain this is a memory. The episode with wearing his old clothes is only a few lines after this bath memory. Thus, as the story shows Bauby blending his past with his present, the language itself also reveals a sense of continuity as memories and reality quickly interchange in the text.

This point is also illuminated in the earlier passage about Bauby’s ability to use his memories of taste and smell to manipulate taste of the current “food” he is swallowing. After telling the reader that he “was a master at recycling leftovers” but now can “cultivate the art of simmering memories,” the language begins to blur what is the past and what is the present. It reads: “You can sit down to a meal at any hour, with no fuss or ceremony...If I do the cooking, it is always a success” (36). To determine whether he is talking about his imaginary “banquet” or about his past cooking talents is difficult. Again, the line between memory and present becomes
hazy. Bauby’s created continuity between his past life and present life becomes “proof” of his personhood (17). To show that Bauby recognizes that a person still exists within his motionless body, the narrative recognizes the same proof by hazily referencing both memories and current events.

Having minimal physical abilities, Bauby must adapt his new lifestyle to include non-physical aspects. Referring to another paralyzed illness-narrative author, Rimmon-Kenan explains: “What is celebrated in his case is a conversion of creativity from the physical to the spiritual” (17). Bauby changes his lifestyle from a physical one into a more spiritual one in three ways: by frequently remembering his past, by using his imagination, and in his reconnecting of certain relationships. I use the word ‘spiritual’ as finding a deep, internal significance in something intangible or non-physical. The idea of a more spiritual life in Bauby’s situation is a life that does not rely on physicality since his physical world is inert, and this is the source of conversion that makes Bauby’s memoir resemble conversion-narrative stories.

Bauby’s imagination, an element of his spirituality, provides comforting escapes from reality. But the narrative still manages to keep the reality of the situation in focus. Bauby frequently describes dreams. In a book of only about 130 pages, there are four dream sequences. One begins: “Stretched out on my bed—I mean, in my cockpit” (DBB 117). Immediately, he is turning his bed into a cockpit. A bed is a place for sleep and rest. A cockpit is a place where someone controls an airplane flying hundreds of miles per hour. His imagination involves mobility and action, which, of course, he lacks in real life. Also, rather than simply identifying himself in the cockpit, the narrative says, “Stretched out on my bed” before showing the reader the details of the dream. This technique takes the reader away from Bauby’s imagination for a moment, forcing the reader to put the dream into perspective: that it is in fact only a dream.
Thus, in the middle of the moment of imagination, which serves as a source of comfort for Bauby, there is a mentioning of his hospital bed, which serves as a source of acceptance.

The dream continues to include other activities that continue to incorporate motion and activity. "I am a phenomenal downhill skier. I can still hear the roar of the crowd on the slope and the singing of the wind in my ears. I was miles ahead of the favorites. I swear!" (117). In addition to the physicality of the dream, it contains descriptions that refer to the senses: the sound of the wind, the roar of the crowd, and the sight of miles of snow. Although Locked-In-Syndrome hinders Bauby from feeling such senses and participating in such activities, his imagination allows him to vicariously experience them. The passage ends with "I swear!", a declaration of fact. The dream is mixed with imagination and the attestation of fact, such as "I am a phenomenal downhill skier." By incorporating these facts in the narrative, Bauby makes it more believable that he actually was skiing down that slope and sitting in that cockpit. Lastly, the exclamation point after "I swear" is curious. Considering that he is communicating this book through blinking his left eyelid, one wonders how his eyelid shows excited speech that is exemplified by an exclamation point. The use of this also pulls the attention away from Bauby's condition and further into the dream sequence. We no longer see a man blinking these words to an interpreter but instead see a man skiing downhill. The narrative technique works the same for Bauby as it does for the reader. The phrase alone, "I swear," is Bauby's attempt to gain credibility with the reader. But why does he need to do that when it's simply a dream sequence, a sequence that is by nature often incredulous and fantastical? The attestation of facts and the use of the exclamation point make the dream more real, and his imagination becomes a very comforting escape from reality because it becomes believable for an instant, both for himself and for the reader.
The scenes of imagination also coincide with Bauby’s restructuring of relationships in his life. One dream puts Bauby in a wax museum. “The characters on exhibition were in street clothes, and I did not recognize them until I mentally put them in white hospital uniforms” (109). First, it is important to notice that wax is able to freeze a moment in time. Returning to my discussion on the narrative technique of blending the past with the present, wax allows for all time to cease. Therefore, the past is the present in this dream. Second, as a former editor of a fashion magazine, street clothes should be able to tell Bauby a lot about a person. But the white hospital uniforms here, which by their nature make everyone look alike, paradoxically, allow him to differentiate the individuals. The figures at the museum are not celebrities—as is typically the case for wax museums—but instead are nurses and orderlies at his hospital. His new self no longer defines people by their clothing. Rather, he must envision everyone in uniforms to identify them. More so, his fame led him into a social circle of celebrities, models, and wealth. This dream gives the impression that his social circle has been replaced, like the wax figures are replaced from celebrities, by hospital staff members. Thus, this dream also is a form of acceptance, a form of Bauby acknowledging his new life that is confined to this hospital room.

This dream serves as a gateway to discussing his opinions of the different orderlies and nurses: which are friendly, which are respectful, etc. Instead of just rushing into talking about the hospital staff, the narrative first uses this fantasy to approach the issue. “They were all there, fixed in wax: gentle, rough, caring, indifferent, hard-working, lazy, the ones you make contact with and those to whom you are just another patient” (110). By putting them in wax, Bauby is able to relate to the hospital staff. They are motionless like he is motionless. And now, having put them on his same level, he can appropriately analyze them and discuss his relationships with
them. His imagination and his dreams allow him to analyze the relationships with hospital staff that are a vital part of his new lifestyle which includes living in the hospital.

These dream sequences reveal Bauby’s conversion to a more spiritual perspective on the world. It is through the intangible, fantasy-esque dreams that Bauby finds comfort with hospital staff members and finds excitement flying planes and skiing down snowy hills. His method of managing activities that are typically physical—talking with the hospital staff and actually executing the flying and skiing—is through the spiritual realm of dreams.

Bauby’s old relationships must be recreated during his recovery, and since they cannot exist in the same manner as before his stroke, they are formed spiritually as well. Notably, Bauby’s relationship with his daughter shifts from the physical to the spiritual. While he receives many prayers from many different people, the one from his daughter closes out the chapter. He thinks: “All these lofty projections are merely clay ramparts, walls of sand, Maginot lines, compared to the small prayer my daughter, Celeste, sends up to her Lord every evening before she closes her eyes” (13). The prayer from his daughter becomes the most important, which is evident from the metaphorical language. Ramparts need to be built out of something stronger than “clay” to protect a castle or to endure the weather. Sand is a poor choice of material to build a wall with since it will easily crumble. The Maginot Line was an ineffective defensive line built by France after World War I to keep out the Germans if they attacked again, which failed since Germany did attack through Belgium to easily overcome the Maginot Line of defense. These metaphors show that something more important is happening with the relationship with his daughter, and that uniqueness is that his relationship with her is becoming more spiritual than it was before his stroke.
Bauby’s condition forces him to change his relationship with his daughter into something more spiritual. By citing her prayer as directed to “her Lord” and not the Lord or our Lord, the narrative reveals Bauby’s lack of religiousness. But in spite of his lack of religious spirituality, Bauby still forms a spiritual connection with his daughter. The next sentence reads: “Since we fall asleep at roughly the same hour, I set out for the kingdom of slumber with this wonderful talisman, which shields me from all harm” (13). The connection arises from their shared hour of falling asleep, a very unphysical connection. More so, sleep itself is a very unphysical activity. Another notable part of the quotation is the “talisman,” which is a good-luck charm and a spiritual source of comfort. Lastly, Bauby references “the kingdom of slumber,” as though he is entering another world. Presumably, this is the world of dreams which we saw earlier as playing a large part in his spiritual conversion. His relationship with his daughter incorporates a nonphysical connection, a good-luck charm, and dreams. This shifted relationship with his daughter is because Bauby no longer can maintain a physical one with her. Thus, in his recovery, he alters his spiritualism in order to connect with his daughter despite his lack of religiosity.

The narrative reveals the restructuring Bauby must do to make his old relationships continue working in his new lifestyle. One instance is during Father’s Day with his family. The energy and movement of his children simultaneously saddens and delights Bauby.

While I have become something of a zombie father, Theophile and Celeste are very much flesh and blood, energetic and noisy. I will never tire of seeing them walk along-side me, just walking, their confident expressions masking the unease weighing on their small shoulders. (69)

The distinction between a “zombie father” and his children who are “flesh and blood” illuminates the changing relationship that they share. Bauby sees his children in physical terms—
“energetic and noisy”—another glaring difference between people and zombies. The zombie reference likely refers to the stillness of Bauby’s gaze, but it comes to resemble much more about the relationship with his children. It is connected to a feeling of acceptance. This sad self-description acknowledges his inability to physically interact with his son and daughter. Also, his explaining about how much he loves seeing his children play is a sign of his acceptance of his condition, because it is his condition that creates the “unease weighing on their small shoulders.” and it is that unease that makes him more appreciative and proud of his children. The reconnection with his children depends on his acceptance of his condition as well as theirs.

This outing with his children takes place on Father’s Day, a holiday never celebrated with the family before his accident and an episode which reveals the altered, redeveloped relationship that he is forced to form with his children. Citing the absence of this holiday in previous years, the narrative continues: “today we spend the whole of the symbolic day together, affirming that even a rough sketch, a shadow, a tiny fragment of a dad is still a dad” (70). This is not a continued function from his past but a new occasion that would not have occurred without his stroke. Here, the narrative counters Frank’s opinion discussed earlier that illness narratives incorporate reaffirming relationships because, in this case, it is a total recreation of Bauby’s relationship with his kids: they are active while he is motionless, and they are spending a “whole of the symbolic day” together that was never spent together like this once before.

The reconnection with his family affirms a self, an existence. In this case, it is the existence of a “dad.” The tiny pieces or “fragments” that hint at fatherhood are still aspects of fatherhood. Despite his inability to play with his children, laugh at their jokes, or speak to them his words of wisdom, he still has managed to feel like a dad. Still in the same chapter in which he called himself a “zombie father,” the reader is thrown into a moment of affirmation and
optimism immediately following a depressing image of acceptance. By doing this, the narrative once again, as shown before in this chapter, coincides moments of acceptance with moments of happiness.

Acceptance is an enormous part of Bauby’s recovery. In moments of comfort (the dreams) and in moments of reconnection, the narrative never forgets the reality of his paralyzed condition. In other instances of his recovery, Bauby creates continuity between the past and the present. The traumatic realities of his present state are blended together with a more joyous past, and thus his present one is restructured. All of these moments of recovery refer back to the greater issue of Bauby’s ability to completely convert his lifestyle following his accident into a nonphysical lifestyle. However, his body never recovers in the story; he never walks, speaks, or breathes independently. Still, the narrative techniques and language make the reader feel that a form of recovery, separate from the recovery of physical health, is happening within the narrative. This is how his text brings up questions about health in general. Bauby’s recovery revolves around two key components: his acceptance of his condition and his subsequent conversion from a physical life to a more spiritual one.

Grealy also uses methods of storytelling to reveal the recovery that she experienced as an adolescent, and it, too, involves a nonphysical form of ‘recovery’. Rather than recreating a lifestyle and looking to the past, however, she must move forward and try to overcome the trauma of a deformed face.

**Grealy’s Recovery**

In *AF*, Lucy needs to overcome the stresses that are a result of her facial surgery. The title of Grealy’s book alone, *Autobiography of a Face*, signifies the salience of her face in the story. It
tells us that it is a personal memoir, and, seeing that it is written by Lucy Grealy, the reader expects her autobiography. But the title deliberately confuses the situation, indicating that the story is being told about a face rather than about a person. It is understandable then that the focus of the story is not solely the progression of the main character, but rather the progression of that character in accordance with her relationship with her face.

Susannah Mintz, who theorizes narrative writing, notices that in AF, “Grealy’s disfigured jaw lives on as a badge of sickness” (Mintz 173). The social abnormalities associated with this “badge” are, for Mintz, the focus of most of the book. Mintz also comments, “[Grealy] demonstrates that her sense of self is inseparable from the condition of her face” (172). I agree with this statement in that the character, Lucy, is completely consumed in her insecurity and awareness of her face. We can assume that this is due to societal standards and the expectation for women to pursue social definitions of beauty, but is also due simply to looking different from everyone else. However, while this statement properly identifies the major conflict in the story as being Lucy living with her face as a “badge of sickness,” it is Lucy’s ability to separate herself from her face that becomes the method of her recovery.

The title shows Grealy, the author, disconnected from her face. Her book is not necessarily an autobiography of her youth but rather an autobiography of a time when her face dominated her thoughts. The narrative contains elements of a conversion narrative because the conclusion, the moment of recovery, is when her face is no longer her most important aspect in the world; her face no longer defines her. The conversion is incomplete in the story since the reader is not sure what does define her in the end, but the reader knows definitively that it is no longer her face.
Mintz disagrees with this theory, citing that it is Lucy’s incorporation of her face into her identity—and not her identity’s separation from her face—that allows her to recover. She writes: “[Lucy] must incorporate her face, in a kind of literal way, as a member of her body, to experience embodiment as inextricable from her self” (181). She continues: “Grealy’s face participates in the establishment of ‘who’ she is,” citing that Lucy discovers her identity and affirms her self through her face. Mintz also comments: “Grealy suggests that there is also no way to disentangle the physical from the psychical” (173). Mintz’s reading of AF sees the final pages of the book, in which Lucy never physically describes her face and expresses a much happier tone than earlier in the book, as evidence of absorption. Instead of feeling insecure so frequently because of her “ugliness” and her deformity, Grealy begins to absorb her face into her personality.

My reading of the book indicates the opposite: Grealy loses her insecurity when she begins to distance her personality from her face. And the first example of this conclusion is the title itself. The title is written by the aged, recovered Grealy, not by the adolescent Lucy who is the character throughout the book. The title indicates that Grealy has distanced herself from her face; otherwise the title page might read “Autobiography of Lucy Grealy.”

The continuous problem for Lucy throughout the book is coming to terms with her disfigurement. In an effort to achieve this, Lucy goes through many different emotions and false resolutions. At times she ignores her physicality, surrenders to the social consequences of it, and even tries to come up with excuses to compensate for it. In one instance of surrender, Lucy concludes, “I was ugly, so people were going to make fun of me: I thought it was their right to do so simply because I was so ugly, so I’d just better get used to it” (145). This resolution proves to be unsuccessful in lifting her spirits and in allowing her to overcome the schoolyard taunts. In
trying to compensate for her ‘ugliness’ and absent love-life, Lucy thinks, “Because I was never going to have love [...] I cast myself in the role of Hero of Love [...] I would become a hero through my understanding of the real beauty that existed in the world” (150). It is noticeable in the tense of “I was never going to have love” that later in the book Lucy does indeed find love and does have many sexual relationships. At this moment, though, the character is trying to overcome her lack of relationships by compensating for it with a unique ability and a greater perspective on life. This moment, however, is ineffective because it is a moment of denial since she, like most people, desires and seeks love throughout the story. This heavily contrasts Bauby’s recovery since, while Grealy admits her faults and moments of denial through Lucy’s character, Bauby rarely shows any denial or limitations.

Lucy’s ineffective attempts to come to terms with her face culminate in the twenty-five or so surgeries that she voluntarily undergoes to try to remodel her face, even after her melanoma is completely removed. These surgeries are not intended to have an effect on her physical health but rather on her emotional one. These surgeries, in addition to the range of actions mentioned just before, all indicate that Lucy’s face consumes her thoughts. The incessant awareness of her appearance is what brings about moments in the narrative that reveal her anguish. It is only when the narrative ceases to be obsessed with Lucy’s face and relinquishes its detailed descriptions to the reader that Lucy’s recovery becomes apparent to the reader. When the narrative stops describing the face and stops obsessing over it, it reveals the end of Lucy’s insecurities as her face no longer is the most important thing in her life.

In the prologue, Grealy quickly shows Lucy’s struggle with her appearance. For the first several pages, Grealy has Lucy hint to the reader the details of her situation without being explicit. The story reads: “I was still blissfully unaware, somehow believing that the only reason
people stared at me was because my hair was still growing in” (AF 6). The reader suspects that there is something different about Lucy, but the narrative does not let the reader in fully (yet).

This gives the reader six pages of seeing Lucy without seeing her face, but the experience for the reader is brief since the next 200 pages make the details of her face and her facial surgeries a frequent topic. It is not until the last chapter that the reader experiences this unknowing of Lucy’s physical features again, and when the narrative returns to that “blissful unawareness.” It is not a fake ignorance on Grealy’s part but rather a narrative technique to show the mature overcoming of her superficial problems.

The reader learns that her short hair is not the reason people stared at Lucy, but that it is instead a perceived ugliness. The way the narrative introduces this ugliness is significant. Lucy tells the reader, “I was my face, I was ugliness” (7). First, this counters the conclusion of recovery in which Lucy separates herself from her face. In the early goings of the book, she defines her self and her identity as the face; the face is all that she sees when she looks at herself and she assumes that it is all that other people see when they look at her. Second, the use of ugliness in its noun form is salient. Lucy does not say that she is ugly, but defines herself as “ugliness.” Therefore, the narrative is creating a connection between centering her identity on her face and her insecure feelings of ugliness. The narrative will later break this connection in the final chapter when Lucy distances her identity from her face and, thus, diminishes her insecurities.

Before analyzing the final chapter, I will show moments in the story that demonstrate Lucy’s fixation on her face. These next few paragraphs will reveal how most of the book focuses on the issue of her face, so much so that Grealy is able to use the final chapter to strongly contrast with the rest of the story in that matter.
Often in the story when Lucy begins to think about her face, the narrative connects the feeling of ugliness to those thoughts. After deciding to eat her lunch every day in a guidance counselor’s office rather than the cafeteria in order to avoid the relentless teasing, the narrative tells the reader, “I felt safe and secure in that office, but I also felt lonely, and for the very first time I definitively identified the source of my unhappiness as being ugly” (126). While Lucy feels safe from the teasing in the office because she is able to hide from the boys who make fun of her, she cannot hide from “being ugly.” Even though she avoids the feelings of ugliness from the boys, her self-perception of being ugly persists. It consumes her thoughts. This is a moment in the story where Lucy is supposedly escaping from her face. However, Grealy shows that Lucy still cannot stop thinking about her face and connects it with a perceived ugliness. Therefore, the safety and security “in that office” is not actual serenity for Lucy. It is only a limited moment of peace.

Lucy is often trying to hide her face from the world but it is always unsuccessful because even if the world cannot see her face, she is still concerned with and aware of her appearance. In addition to the moment above in the guidance counselor’s office, Lucy tries other ways to avoid the problem of her face. While her hair is still growing in, Lucy buys a hat to cover her baldness. “My hat was my barrier between me, and what I was vaguely becoming aware of as ugly about me, and the world. It hid me, hid my secret...when people made fun of me or stared at me I assumed it was only because they could guess what was beneath my hat...as long as I had it on, I felt safe” (106). The hat serves as a veil of security for Lucy. She is telling the reader that while it was on, she felt safe. However, the wording of the narrative brings about some doubt over this statement. The reader, along with Grealy, is aware that Lucy’s hair is not why people stare at her, but it is her face that is the reason. A hat covers only her hair (perhaps a small part of her face).
Thus, this veil of security, similar to the guidance counselor’s office, is not absolute and is a faulty solution to the problem since, despite the hat, Lucy still feels insecure because people continue to make fun of her or stare at her. Because Lucy tells herself that her hair is the problem and not her face, she is not able to manage the problem properly. The narrative continuously splices together moments of Lucy’s confidence with admissions of ugliness, which reveals the inadequacy of such confidence.

Above all, Lucy’s insecurity about her face is indicated by the numerous surgeries that she undergoes to reconstruct her appearance. During her first visit to the surgeon, she learns about the skin grafts and details of the surgery. Lucy describes the surgery in great detail in nearly an entire page of specifics regarding the procedures (which would include several operations). “In the first operation, two parallel incisions would be made in my stomach. The strip of skin between these incisions would be lifted up and rolled…the two incisions would be together down its side…six weeks later, one end of the hand would be cut” (154). This descriptive, methodic tone continues on until finally an expression of emotion comes in at the end of the paragraph when Lucy realizes how long the procedures will last. “Ten years! I was horrified…Did I have to devote the next ten years of my life to one surgery after another?” (154). The sudden burst of emotion contrasts the methodic detailing done just before. Grealy is showing Lucy think through the process of her surgeries logically and scientifically at first, giving the impression of them as a simple fix to her problems. Then, Grealy shows Lucy thinking about the operations from a more realistic standpoint and Lucy is astonished at the idea of spending ten years of her life going in and out of surgeries.

Like before with the guidance counselor’s office and the hat, the surgeries seem to be a logical fix to Lucy’s dilemma with her face and her identity, but eventually the solution is
realized to be futile. And, as before, the issue of ugliness comes up during this moment in the story. Lucy hurries to a library to learn more about the procedure and see pictures of other patients who had gone through this ten-year process. “The people in the photographs looked like freaks” (155). Ugliness connects with freakishness, and Lucy is horrified by the appearance of these patients. At the end of this episode, Lucy cries out, “For the first time I wished I were dead.” The theme in these moments in the story is that a source of hope is quickly transformed into a moment of anguish. The surgeries that would “fix” her problem are difficult and lengthy, making her wish she were dead. The hat covered her hair but did not stop people from making fun of her. And, the guidance counselor’s office hid her from the teasing boys but it is in that office that Lucy realizes her ugliness is the source of her problems.

It is in moments of supposed refuge that Lucy’s sadness over her ugliness is greatest. All three of these moments of hope end up becoming moments of realization that only further her awareness about her deformed appearance. Also, all three of these moments of hope revolve around hiding her face from others. The real solution ends up being hiding her face from herself. Up until the final moments of the autobiography, her attempts to cover up her appearance are all directed outward, and her poor self-perception is not being dealt with. In detaching her identity from her face and not personally noticing it, Lucy is able to recover from her trauma.

In the final chapter, Lucy begins to distance her identity from her face. As the recovery begins, Lucy says, “This was me, this was my face, like it or lump it” (212). When she says “this was me,” it is a clear assertion of self. The use of the verb “lump” implies that you can either like Lucy’s personality or lump it together with her face. The negative choice is the lumping together of the “ugliness” of her face with the “beauty” of her personality. This is the moment

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4 Also, while it is interesting that the assertion is in past tense, the entire story is told in past tense which makes the fact less relevant. Still, it makes the reader wonder whether Lucy Grealy still felt this way years later when she wrote the book.
when the conversion takes place, when Lucy begins to see that her self is more important than her face. Also, it is interesting to compare this line to the line of page 7, “I was my face, I was ugliness.” The parallel is clear. However, in the later part of the book, Lucy is no longer defined by her face or by ugliness; rather, “this was me,” and “this was my face,” are two separate phrases. Unless someone wants to “lump” them together, they should be seen as distinct and mutually exclusive.

Later on in the chapter, the narrative more explicitly separates Lucy’s identity from her face by incorporating mirrors. The title of the chapter is “Mirrors.” However, the irony in the narrative is that mirrors become useless for Lucy. She lives her life “not without my image, without the framework of when my face gets fixed, then I’ll start living” (221). And, without this framework and this mindset, she is able to ignore the image in mirrors. This passage, connected with the ignoring of mirrors, shows that Lucy’s recovery is from distancing herself from her face, not letting it define her. “I found that I could stare straight through a mirror, allowing none of the reflection to get back to me” (221). The narrative uses reflections to make a point that Lucy’s recovery is a result of no longer consuming her thoughts with her appearance. This moment in the story comes right after Lucy, for the first time, rejects a surgery. By doing so, Lucy is also rejecting the superficiality of the world. In the final moments of the book, Lucy sits in a café and gets the attention of a man, she says,

What was he actually seeing in me? I asked myself this old question, startlingly, for the first time in my life, I had no ready answer. I had not looked in a mirror for so long that I had no idea what I objectively looked like (222).

There are a couple notable words in this passage. First, the question is an “old” question, no longer part of her language. The concern over how someone sees her no longer exists. It can also
be read as being an old, familiar question. In this case, Grealy is putting a spin on the question because the word “seeing” does not only have its familiar meaning, rather a dual-meaning that includes the literal definition of “seeing.” What does he think of the face that he sees? Also, the word “objectively” is significant. This reveals the conversation taking place for Lucy. Grealy shows Lucy going through a conversion from worrying solely about her face in an objective sense to looking inward in a subjective sense at her persona. In fact, she asks, “What was he actually seeing in me?” rather than ask, “What was he actually seeing on me?” The question is not directly about her exterior appearance.

Lucy, in this passage, seemingly cannot even identify herself in a mirror. She doesn’t know what she looks like. The same is true for the reader. After her final surgery, there are no descriptions of her skin grafts, the deterioration of such grafts, her ugliness, or any physical descriptions at all. The reader loses the ability to picture Lucy’s face in these final pages. This drags the reader’s mindset back to the first six pages when the reader was “blissfully unaware” that Lucy was considered ugly (6).

Lucy’s final moments in the book reveal a recovery. Her greatest struggle throughout the story is socializing, especially with boys and men, since males are the source of most of her teasing. But the book ends with a scene in which she shares coffee with a man, and the narrative tells us that Lucy is “feeling the warmth of the cup against [her] palm” as the two chat (223). This passage of warmth gives a comforting feeling. She compares her inability to see herself in the mirror to dead people in films who only know they are dead when they can’t see themselves in the mirror (222). Her face is “dead.” The Autobiography of a Face is over but the story of Lucy Grealy continues. As the troubles with her face die, she shares a pleasant conversation with a man. Her recovery depends on her inability to recognize herself in the mirror, her ability to
distance her happiness and her identity from her face. It is at this point that the narrative reveals her recovery and the restructuring that has taken place: her life is restructured in order to no longer depend on her appearance.

Between Bauby’s new lifestyle and Lucy’s changing attitude towards her face, the concept of recovery becomes more complex than simply curing an illness. Bauby’s illness is never cured, yet the reader still witnesses moments of growth in his confidence, his relationships, and his lifestyle. Lucy’s character also vastly changes, but her disease is technically gone before the real struggle of the story begins. In bringing up such questions about recovery, the two texts question what defines illness and what qualifies as an illness narrative. Instead of recovery being a return to a previous state of health, it is shown in these texts as a conversion to a new perspective of what is health. If recovery includes improving your lifestyle and overcoming such struggles, then the illness narrative may be a larger genre than previously thought.

More specifically, Grealy’s story of recovery brings up questions of beauty and self-perception as well. These issues are not exclusive to jaw cancer or even to illness but can be assumed to affect all of our lives in some way. The ways in which these two texts connect to audiences that are not directly associated with illness is the subject of chapter 3 in this thesis and will be addressed therein.

Overall, these narratives are revealing how the authors manage their lives with illness. They work by demonstrating how illness changed their lives for the worse and then how the individuals are able to overcome those unfortunate outcomes. One negative component of illness is a loss of agency and of voice in the world. The reclaiming of this agency connects to the conversion-like recoveries here in the sense that it is another example of finding a way to manage illness. This, also, is the central focus of chapter 2.
Chapter 2

The Loss of Agency and Authority within Illness

Defining Voice

Jean-Dominique Bauby, while living with locked-in syndrome in the hospital, is peacefully sleeping one morning when he wakes up to find a surgeon stitching his right eyelid. A doctor’s needle and thread delicately close up his paralyzed right eye, and the subsequent terror that Bauby experiences from this unannounced procedure is alarming to read. Unable to speak and fearing that the doctor will also sew his left eyelid shut (Bauby’s “only link to the outside world” because it is his sole mode of communication), Bauby helplessly waits for the procedure to be over (DBB 53).

In the midst of this procedure, Bauby is voiceless because of his inability to speak, gesture, make a facial expression, or even make an arm motion. He physically cannot express his terrifying concern to the doctor or ask the doctor questions about what is happening to him. And yet there is a way in which all illness narratives involve patients experienced a more abstract form of voicelessness. It is the narrative of The Diving Bell and the Butterfly—written after the procedure takes place—that allows Bauby to recapture this type of voice, which was stolen by his illness.

When using the term “voice” in this chapter, I am referring to the ability to express one’s own feelings and opinions, to have a say in the situation. It connects to a sense of agency in the world and to an authority over one’s own condition. Bauby, Grealy, and most patients in general lose aspects of their voices (to different degrees) as a direct result of their illnesses. As I will show, Grealy and Bauby have a more difficult hill to climb to reclaim that lost voice than most patients. Bauby achieves this through an optimistic recognition of the hidden power in his mind.
Feeling worthless in a useless body, Bauby refutes that worthlessness through his narrative to give him self-validation. Grealy, on the other hand, shows Lucy overcome her immaturity by giving the narrator a reflective, self-aware attitude towards her childhood. While Bauby and Grealy use different strategies to reclaim voice, that reclamation is prevalent in both of their stories.

In pursuing this reclamation, the authors use narrative writing as a tool to achieve something. Reclaiming voice gives the actual writing of the narrative a purpose; it gives the authors the ability to exhibit control over their difficult situations. Illness narratives are not simply telling one’s story, but also serve to achieve this display of reclamation for that person.

**The Medical Narrative and Voice**

Before I turn to the narratives themselves, it is important to note that a figurative loss of voice is fundamental to all medical patients. What is commonly called by sociologists as “the medical narrative” does not include Bauby’s and Grealy’s emotional experiences. I will define the medical narrative as the objective, scientific, symptom-based story that a doctor uses to explain the progression and the treatment of a disease or disability. It includes the diagnosis, the categorized symptoms, and any other dispassionate conclusions about the illness.

Recall the earlier situation for Bauby in which his eye was being stitched shut. In Bauby’s “medical narrative,” the event would be described as a successful procedure in that it prevented any infections from affecting his right eyelid. From the ophthalmologist’s point of view, the patient is treated, the eye will not get infected, and it is a job well done. From Bauby’s point of view, by contrast, this procedure is ten minutes of grueling panic and confusion. His narrative is completely unlike the medical narrative.
In the medical arena, the doctor’s voice often overshadows the patient’s. Bauby’s and Grealy’s works attest to the possibility that the illness narrative functions as a way for patients to reclaim that lost voice. Of course, they also address the more significant losses of voice caused by Bauby’s paralysis and Lucy’s immaturity. In doing so, the illness narratives express an element of experience that is absent from the medical narratives; in fact, they help reveal illness as being an experience rather than solely a list of symptoms and diagnoses on a medical chart.

The medical narrative arises from a patient-doctor relationship that gives power and voice only to the doctor. Judy Segal describes the patient-doctor interaction by noting, “The patient is […] the physician’s audience and is for that reason also a construct of the physician” (Segal 37). The patients are the “audience,” the listeners in this relationship. The doctors are, then, the sole voices. By reducing the vocal contribution of patients in their own medical treatment to only being a subset of the doctor’s agency, the doctor holds the authority in the situation. In addition, by noting that patients are “a construct of the physician,” Segal argues that the patient’s identity in the medical narrative depends on the approach and the opinion of the physician. It forces the patient’s story to be simply a recitation of the medical narrative, not allowing for the patient’s own words or opinions to carry through—instead, they speak the words of the doctor from a different mouth.

Talcott Parsons, a sociologist from the mid-twentieth century, is less critical of doctors than Segal when he defines the “sick role” of the patient in his book, The Social System. In defining the “sick role,” he notes: “[the patient] is not only generally not in a position to do what needs to be done, but he does not ‘know’ what needs to be done or how to do it” (Parsons 441). Parsons’ description implicitly justifies the power granted to the physician. Obviously, the patient cannot determine diagnoses. And, according to Parsons, the specialized language of
medicine is typically unknown by the patient. Thus, the medical narrative is understandably constructed by the doctor as the patient’s voice is left out.

Arthur Frank, a contemporary sociologist who focuses on illness narratives, analyzes Parsons’ “sick role” and discovers the significance of the illness narrative in dictating the experience of a disease or disability. According to Frank, the illness autobiography proves that the medical narrative provides an incomplete account of illness. Frank says: “The postmodern experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell” (Frank 6). What’s relevant to my purpose is that his description reiterates the necessity of understanding “experience” to fully understand illness. Further, it also helps us see that the writers of illness narratives are expressing personal stories that only they have the power to portray. Frank explicitly says that the “postmodern” condition relies on “ill people” recognizing the value of their own stories. Their family members’, friends’, and doctors’ stories cannot fully represent the illness experience. Only stories from the ill people themselves can create a more complete understanding of that experience.

The questions then arise: who is this more complete understanding for? Is it for the doctors whose narratives are lacking? Is it for other people with similar illnesses? This concern of audience, the question about the ideal reader of these narratives, will be addressed later. It is the central item in chapter 3 of this paper.

This chapter, on the other hand, will show how the authors feel a need to bring to the surface a more complete understanding of illness. Frank specifically attacks Parsons’ theory of the “sick role,” citing as its major flaw the fact that it “does not include helping patients learn to think differently about their post-illness world” (Frank 6). Parsons’ “sick role” construes the

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1 Since on page 4 of his book Frank explicitly avoids defining postmodernism, I will address his remarks without questioning their relevance to postmodern theory.
physician as someone who returns the patient to his normal life and normal obligations. In Parsons’ mind, the medical narrative seeks to heal a person by restoring the status quo. For Bauby, this restoration is nearly impossible because of the permanence of his condition. For Grealy, this restoration is irrelevant because her “post-illness world” becomes her greatest challenge, bringing about issues of disfigurement and family dysfunction (discussed in chapter 1). For these two writers, and, in Frank’s mind, for most ill people, Parsons’ “sick role” does not apply. It poorly represents the patients. Not fulfilling the “sick role” leads to “[patients] feeling a need for a voice they can recognize as their own” (Frank 7). It is this conclusion by Frank that proves the need for patients to express their own voices and reveal their agencies. Writing illness narratives is a successful method for this.

All of these theories come together to demonstrate that the medical narrative does not leave room for a patient’s voice. Rather, the patient’s voice, which comes out in illness narratives, is a reactionary voice driven by the medical narrative. The medical narrative’s construct contributes to the need for reclamation of voice, but in Bauby’s and Grealy’s cases, the loss of voice is heavily exacerbated by the more salient issues of Bauby’s physical inability to speak and Lucy’s immaturity during her condition. I will now turn to how it is achieved differently in AF than in DBB. In AF, the reclamation of voice is shown through the maturation and development of Lucy’s character. In DBB, the reclamation of voice is shown through Bauby’s attempts to validate his worth.

**Bauby’s Reclamation of Voice**

Jean-Dominique Bauby, a once powerful and successful businessman, loses more than his mobility during his illness. He also loses his status in the world. His loss of speech, which is
directly tied to his total loss of control over his body, causes him to question his worth and value in society. Elaborating on Bauby’s need for validation, literary theorist Valerie Raoul writes: “His previous experience of power, control, and mobility is a handicap rather than an asset, now that he must accept being powerless, immobile, and controlled by others. His former eloquence, wit, and literary skills also seem to have become superfluous, as long as he cannot communicate” (Raoul, et. al 189). Raoul points out that Bauby has lost his once-exerted power in the world because of his new condition. She states that he does not regret losing that power as much as he struggles to live on without his typical modes of communication and authority.

At some points in the narrative, Bauby directly ties his frustration over his physical condition to his once authoritative status. While going through speech therapy, Bauby writes: “I am struggling with the letter l, a pitiful admission for an editor in chief who cannot even pronounce the name of his own magazine” (DBB 40).2 In reality, Bauby struggles to pronounce nearly every letter in the alphabet, but he is specifically obsessing over the letter “L” because it reflects a greater frustration for Bauby: the loss of his profession. His inability to run his magazine because of his paralysis is vital to his sense of losing control and authority. It is the transition from powerful to powerless that is difficult for him. As Raoul states, he is now “controlled by others.” Bauby’s physical loss of voice hinders him from speaking on his own behalf about his condition and from feeling a sense of agency in his life.

Bauby asserts his worth and revalidates himself by showing in his book that within his useless body, a strong mind and a strong voice exist. The title of the book, *The Diving Bell and the Butterfly*, reveals this paradoxical dynamic. A diving bell is an antiquated instrument, an airtight chamber that allows transport for divers underwater when it is lowered beneath the

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2 Bauby was the editor in chief for *Elle* magazine, which has the same pronunciation of the letter “L” in both French (Bauby’s native language) and English.
surface. Here, it provides the image of entrapment, representing his immobile body. The butterfly represents his fluttering mind and his mind's capability to escape the imprisonment of his body. However, while a diving bell can be restrictive, it is also a tool for exploration. It can be seen as both limiting and enabling.

Interestingly, the diving bell (his physical entrapment) enables Bauby's because butterfly-like mind. Immediately following the definitions of the “diving bell” and “the butterfly,” the narrative begins to drift off like a butterfly. Bauby begins to imagine going to a myriad of places. “You can wander off in space or in time, set out for Tierra del Fuego or for King Midas’s court…visit the woman you love, slide down beside her…build castles in Spain…discover Atlantis” (5). Early on in the book, on page 5, the reader witnesses the strength of Bauby’s imagination and quickly understands that his futile body does not reflect a futile mind. In fact, some of Bauby’s imaginary destinations, like Atlantis and space, are places based on fantasy or are unlikely destinations for the typical person. Bauby, therefore, is hinting at the idea that his mental capacity exceeds the capabilities even a functioning body would have because, without his stroke and his paralysis, he would never be able to visit such fantastic places. The narrative reveals Bauby’s source of empowerment as his mind.

In the midst of discussing his “diving bell,” the narrative frequently uses images of mobility. He ends this imagination sequence by saying “Enough rambling” (5). Literally meaning ‘to wander or walk around aimlessly,’ “rambling” gives the impression that Bauby’s mind is going for a walk. The word gives energy and activity to a motionless man in a hospital bed. With imaginary destinations like Atlantis and space, Bauby is able to swim and fly as well. Also, his mind resembles a voice, since “rambling” often characterizes speech. The power of his
mind to mobilize himself and grant himself speech obscures the image of a useless, paralyzed man.

Voice, however, encompasses more than speech and mobility, it also represents agency. Before displaying authority to the people in his life, Bauby first shows the reader the presence of his voice. The title of the chapter in *DBB* where Bauby’s eye gets stitched shut indicates a desire by Bauby to regain that lost voice and bring it forth by using the narrative. It is titled “Voice Offstage.” The “voice” is Bauby’s. His opinions, his feelings, and his perspective are “offstage,” shut out by his illness from the experience of sewing his own eye. By citing his voice as merely “offstage,” Bauby is acknowledging that it was absent during the moment, but not inexistent. It is separated, detached, but still looming, waiting to come out. Bauby’s narrative description of the experience in this chapter brings his voice onstage. Like the images of mobility before, Bauby makes his voice feel present to the reader.

When his ex-colleagues start rumors about his health, Bauby uses the reader as a witness in order to prove the rumors false. His old co-workers refer to him as “a complete vegetable” (82). Understandably, this infuriates Bauby, who feels that the word indicates that he “belongs on a vegetable stall and not to the human race” (82). In his language, he demonstrates his fear that people doubt his intelligence and his personhood, whether he’s even part of “the human race.” To counter his co-workers assumptions, to assert his authority on his illness, and to prove them wrong, he writes *DBB*. Bauby explains: “I would have to rely on myself if I wanted to prove that my IQ was still higher than a turnip’s.” The existence of this book and of his wit in this instance fulfills Bauby’s goal to confirm, for the public, his intelligence.

Bauby’s placement of this chapter is a narrative strategy meant to assert his self-worth at a point when his readers will believe him. The chapter, titled “The Vegetable,” is the nineteenth
chapter of the narrative. As a reader, one is already aware of Bauby’s un-vegetable-like mind after reading the eighteen preceding chapters. The placement of this chapter is significant in demonstrating Bauby’s determination in proving his worth and reclaiming authority over his true situation. While anyone hearing this story would condemn Bauby’s co-workers as cruel, the placement of the chapter towards the end of the book allows the reader to recognize the co-workers as wrong. We, as readers, have been seduced by his voice in the preceding eighteen chapters, and once we experience how others perceive him in Chapter 19, we are able to fully appreciate his worth. Bauby organizes his story methodically, forcing the reader to never doubt his intellectual capabilities. And this chapter causes the reader to finally recognize what he or she has been witnessing all along: a man with a dead body but not with a dead mind. This strategy distracts the reader from Bauby’s weakened body, placing the attention of the narrative onto his mind and his intelligence.

The conclusion of this chapter counters the rumors of his co-workers of him being useless while maintaining images of mobility. In closing out this chapter, Bauby describes a countless amount of letters he receives in the mail from friends. Bauby finds strength and happiness in knowing that people keep him in their thoughts. This helps validate his existence and his personhood for himself. In addition, the letters give him pride and are tools for refuting the comments about him being a vegetable. He explains that he “hopes to fasten them end to end in a half-mile streamer, to float in the wind like a banner raised to the glory of friendship. It will keep the vultures at bay” (84). The banner is a symbol of achievement. Bauby sees the existence of these letters as evidence to prove the co-workers’ vulture-like thoughts wrong. There’s significance in the choice of the term “vultures.” The colleagues’ words tear away at Bauby’s dignity like vultures tear away at a carcass. They see Bauby as dead because his body is dead.
But the letters of friendship prove his liveliness, and fend off the vultures that incorrectly perceived him to be lifeless. To fend them off, Bauby dreams of “[Fastening the letters] end to end in a half-mile streamer,” a job that would require a great amount of physical effort. The act of streaming the letters over a half-mile distance disguises his immobility for the reader.

The general structuring of the book, in addition to the placement of this chapter, reflects Bauby’s need for control. As mentioned earlier in the introduction of this thesis, the book has no chronological order. In fact, the second-to-last chapter narrates the car accident that began this situation because Bauby happened to be driving when his stroke occurred. Lacking this typical order, the narrative gives Bauby control over time and place. The timing of events no longer applies to Bauby. This ordering is another example of Bauby reclaiming authority over his situation and, amongst his severe illness, finding methods to regain control over some elements of his life.

In addition, Bauby’s voice comes through very strongly through moments of humor. Bauby uses humor frequently rather than dwelling on his misery and his pain, and this narrative technique makes Bauby more likeable for the reader. The opening line of the chapter, “Voice Offstage,” is an example of the reclamation of voice that Bauby aims to achieve. Bauby opens: “I have known gentler awakenings” (53). The huge understatement here of Bauby’s situation is noteworthy. In this sentence, the devastating image of a completely paralyzed man suddenly being woken up to his eyelid being stitched shut as “terror swept over [him]” is possibly a coping mechanism by Bauby, the use of humor to avoid approaching the seriousness of his illness. But more importantly, his understatement is a source of humor that mocks the doctor’s discourteous procedure. Bauby is using his voice here to acknowledge the horror of this experience in a
manner that exemplifies his wit and his intelligence. He makes the reader look at the doctor as inferior and dense compared to Bauby himself who comes across as the opposite.

Further into the chapter, Bauby mocks the ophthalmologist again, noting that the doctor “carefully packed away his sewing kit” after the procedure (53). The mocking is in the word “carefully,” as Bauby is pointing out that the prudence and care that was granted to him did not match up with the carefulness given to the doctor’s inanimate toolkit. Bauby claims a voice through his anger and sarcastic attitude towards the doctor. His words describe the procedure with emotion and opinion, which are nonexistent when the actual stitching takes place because Bauby’s words are held back by paralysis. In being the narrator of the book, Bauby wields a sort of power since we never hear the doctor’s perspective. With this power, Bauby is able to assert an emotional strength by appearing calm, confident, and funny.

His humor often connects to underplaying a situation that is much graver than described, which shows how Bauby prefers to be witty rather than dwell on his problems and weaknesses. One more example of humor is after weeks into therapy. Bauby has lost sixty-six pounds in about five months due to his nourishment intake of only essential vitamins and minerals. Bauby’s reaction: “When I began a diet a week before my stroke, I never dreamed of such a dramatic result” (15). Once again Bauby is underplaying the significance of his condition in order to showcase his humor and in order to avoid having to write a sad description of his frail, extremely thin body that is a result of his lack of mobility.

This humor connects to the issue of reclaiming voice because it displays Bauby’s control over his writing, his words, and his perspective on his world. The illness took away his ability to communicate efficiently, but he gains back his demeanor and his personality in the narrative writing itself. Bauby humorously describes the first time he is ever put into a wheelchair as he is
“dumped...unceremoniously” back into his bed (8). As his immobile body is being put back on the bed by three orderlies, it makes Bauby envision “movie gangsters struggling to fit the slain informer’s body into the trunk of their car” (9). The expected depression of this moment makes the reader predict a solemn or strictly factual account. Instead, Bauby amusingly compares his body to a dead mafia informant. The humor in this scene is tied together with an image that recognizes the illness’ grasp on Bauby’s voice. An informer is notorious for his words and his speech; “informing” is a mode of voice. The mafia bosses, who metaphorically represent his illness, silence the informant by killing him. The orderlies, who represent the mafia henchmen in this metaphor, are carelessly “dumping” Bauby’s body, which exemplifies Bauby’s fear of being invalidated and of being perceived to be as good as dead. Once a man of power and authority as the editor of Elle, Bauby is cut down and his voice is taken from him by his illness. His humor and his narrative help him regain a voice silenced by the gangster-like stroke that paralyzed his body.

Humor, as well as his assertion of authority, helps Bauby arise above a label that is stigmatized: Locked-In-Syndrome. This phenomenon of needing to assert one’s identity against the limiting label of illness is common for patients. Susan Sontag notices how metaphoric terms associated with illness can be damaging. She says: “My point is that illness is not a metaphor, and that the most truthful way of regarding illness-- and the healthiest way of being ill-- is one most purified of, most resistant to, metaphoric thinking” (Sontag 3). With the name “Locked-In-Syndrome”, Bauby’s condition takes on the metaphor of imprisonment and inability; the name does not leave room for a “key” to cure him. A metaphor like this one is inaccurate in assuming that he has no mode of freedom, and thus irresponsible. Bauby must overcome this metaphoric thinking and overcome the lack of agency that such a label implies by showing the world his
butterfly-like mind, his strongly developed character, and his humor which allows Bauby to avoid discussing the severity of his condition altogether.

Bauby’s reclaiming of voice has a very positive feel in the book. His discussion of the “dying bell” accompanies fanciful visits to exciting faraway places. His rebuttal against his gossiping co-workers is triumphant. And his humor has a light, playful feel to it. In doing so, Bauby’s method of reclaiming voice revolves around showing his audience that he is happy, that he is still lively. By proving this to his readers, he achieves his validation because we are witnesses to his reclamation. This assertion of authority connects to the idea of recovery discussed earlier in Chapter 1. Recall Simmon-Kenan’s comment that illness autobiographers “redefine the present in terms of the past” (17). He is restructuring the present by displaying a macho, controlled, confident persona, as if he has everything in his life in order. In reality, he is completely paralyzed and cannot even write this book without the help of a specialized alphabet and a translator. In reclaiming his agency and his voice that he once had as the editor of an international fashion magazine, Bauby is also recovering in Simmon-Kenan’s terms. He is recovering his past role as an executive in his words and in his confident, optimistic tone of voice that delivers these words.

Unlike Bauby, Grealy does not use humor or optimism to reclaim her lost voice. In fact, it’s Lucy’s immature use of humor that causes her to lose control over situations; her immaturity in general as a young girl during her illness is what causes her to lose authority over her situation.³ To regain that control, she must reveal a sense of maturity, and it comes through in more depressing terms than Bauby’s reclamation.

³ Recall from the introduction that the author of AF will be referred to as Grealy while the protagonist of the story will be referred to as Lucy to better create a distinction between the writer and the character.
Grealy’s Reclamation of Voice

Grealy depicts Lucy’s cancer as less debilitating than Bauby does his paralysis. Lucy is physically able to speak, to gesture, and to express herself. However, the unique condition under which Lucy loses her voice is her youth. The voice in *Autobiography of a Face* is that of an adult reflecting back on her childhood years, and Grealy shifts constantly between granting that voice an adult’s and a child’s persona. She uses a childish, confused personality as the narrator when trying to illuminate the issue of Lucy’s emotional immaturity. She grants the narrator an adult, self-aware persona when revealing the maturation of Lucy’s character. The adult voice is confessional and self-punishing, acknowledging her childish shortcomings and blaming herself for her loss of control over her illness. This strategy forms the basis for Lucy’s reclamation of voice.

By being treated with very little respect because of her age, Lucy is prevented from having any sense of authority during her illness. Both parents and doctors hold back information from her. In fact, Lucy does not even find out that she had “cancer” until nearly a decade after her diagnosis because doctors and parents alike used words like “sarcoma” and “malignancy” to hide the truth from Lucy’s knowledge. The narrative reads: “Some years later [after the diagnosis], I was leafing through the paper at the table. Someone dated an event as something that had happened ‘before Lucy had cancer.’ Shocked, I looked up” (43). The manner in which Lucy finds out is significant. She remains untold by anyone; she instead discovers the details of her illness on her own. Without even the knowledge of her illness, Lucy is unable to claim any sort of agency. The perceived lack of respect given to her by her family and her doctors in this case reveals how her immaturity and age hindered her ability to obtain a true voice. For example,
Bauby, on the other hand, who is a middle-aged man when his illness strikes, is given a full description of his situation (albeit amidst a brief sense of false hope).

Susan Sontag, in her discussion on metaphors associated with illness, analyzes the power of the word ‘cancer.’ She says of some doctors during the 1970’s (at the time her book was written), “[Some] recommend that physicians generally abandon ‘names’ and ‘labels’ [...] It is not naming as such that is pejorative or damning, but the name ‘cancer’ ” (Sontag 6-7). Sontag points out the significance of the word ‘cancer’ and even cites that some doctors in Europe during this time would intentionally hold back using such words in diagnoses unless the patients were “exceptionally mature and intelligent” (7). The reason this applies to AF is because Lucy is not exceptionally mature and because the events in this narrative occur around the same time that Sontag is writing. The labels associated with certain diseases were considered only to be used with the most courageous and mature patients. Sontag’s analysis demonstrates that the withholding of information from Lucy about her own disease is tightly linked with Lucy’s perceived maturity and growth.

Lucy’s voicelessness, resulting from immaturity, is exposed during Lucy’s first chemotherapy session. Her reliance on adults to help her demonstrates Lucy’s lack of control. After the chemotherapy doctor, Dr. Woolf, exits, Lucy says, “Someone helped me put my clothes back on” (76). Considering that the reader was only aware of Dr. Woolf, Lucy, and Lucy’s mother’s presence in the room, it is likely that her mother helped her with her clothes, intensifying the image of Lucy’s dependence on adults. However, by saying “someone” and not “my mother,” the narrative demonstrates that it does not matter who is helping Lucy put her clothes on even though it’s obvious that it’s her mother. All that matters, instead, is that Lucy did not put them on herself, and the ambiguity of “someone” helping her accentuates the
helplessness that she feels. Furthermore, her pain is internalized. She’s never able to express her contempt for the doctor or her difficulty with the pain. Before the injections, Lucy tells the reader, “I was asked to strip down to my underwear, which I did, feeling humiliated and exposed” (74) Then, afterwards, the doctor silently watches as her body begins to “shake with heaves so strong they felt more like convulsions” and as she vomits into a metal basin (76). But Lucy only tells us, the reader, about her humiliation and the gravity of her pain. She does not tell the doctor. She does not tell her mother. In doing so, Lucy is completely voiceless when it matters. Only the reflective narration can express her pain, while, in the moment, she is unable to communicate effectively with her mother or Dr. Woolf.

The description of Dr. Woolf before the chemotherapy takes place reveals the intimidating power of adults for Lucy, only a young girl. His name alone reflects a frightful image for children: a big, bad wolf. More specifically, his behavior is criticized:

Dr. Woolf’s manner was gruff and unempathetic. The first time he examined me I could only flinch at his roughness as his large fingers pressed hard into my abdomen, pried open my still stiff mouth. His appearance didn’t help. Tall, large-featured, and balding, he had a peculiar large white spot on his forehead […] his nose was tremendous, his lips invisible. He scared me. (74)

The adjectives used to describe Dr. Woolf in this scene are undeniably showing Dr. Woolf’s threatening figure in Lucy’s mind. Words like “roughness,” “large” (which is used three times), “tall,” and “tremendous” give the reader the image of a towering, unapproachable, and daunting older man. Lucy ends the paragraph with a short, direct proclamation that Dr. Woolf “scared me.” It is the presence of an adult, the “balding” of his forehead, and the largeness of his body that seal Lucy’s lips, helping silence her later on when the session is over and she is left
helplessly in pain. As the procedure continues, and Lucy goes through the humiliation and pain discussed before, she tells the reader of her anguish but never speaks up or cries out to the two adults in the room—her mother and Dr. Woolf. She also never criticizes the doctor for his “unempathetic” behavior or for his “roughness.” Her childish fear of the doctor seemingly hinders her voice.

The narrative here, like the one in Bauby’s chapter, “Voice Offstage,” comes long after the actual experience. It is told in retrospect. By telling the reader so many details regarding her pain during this therapy session but never having expressed herself when it actually took place, Grealy develops a theme of reclamation of voice. In describing Dr. Woolf’s manner, his behavior, and the pain of chemotherapy, Lucy speaks out about something that was silenced during the actual experience. Since the book is, for the majority, told in past tense, a passage like this one indicates that Grealy recognizes the need to go back and say what was not said before.

To amplify Lucy’s immaturity in this situation, Grealy depicts the child-like persona of Lucy in the narrative as unreliable. It is hard to believe that there is a doctor as cold-hearted as Dr. Woolf. It is also hard to imagine that a doctor would watch an eleven-year old girl break down crying, then vomit all over the floor during her first chemotherapy session, and simply walk out of the room unsympathetically “puzzled” (AF 76). This shows that Lucy’s perspective is a childish reaction to the “evil doctor” who causes her this pain. It suggests that the whole scene is told through the eyes of Lucy, through the voice of a frightened young girl, and it is plausible then that this depiction of Dr. Woolf is not reliable. By reverting to the adolescent voice of Lucy in this section, Grealy is allowing the reader to recognize that her voice is not only hindered by adults but that, because it is that of an immature child, her maturity level distorts
situations with adults. Reverting back to Lucy’s voice is not a nonfiction account but rather a narrative technique by Grealy uses to illustrate a theme about age and voice loss.

Lucy lacks control and awareness during this chemotherapy session, but she actively refuses control at another moment in the narrative by using disregard and denial to avoid problems, a direct sign of her youth. In this instance, pertinent information about Lucy’s illness is once again kept from her. However, an admirably caring nurse tries to approach Lucy about the extent of the surgery that will remove her cancer. The nurse asks Lucy: “‘Do you know you’ll look different afterward?’” (AF 54). The nurse is obviously diminishing the “difference” that Lucy’s face will have, considering she is about to lose nearly a half of her jaw. The nurse is doing this to try and gently break the news about the disfigurement that this ten-year-old girl is about to experience. Lucy’s reaction is expectedly immature; she refuses to listen to the nurse and instead turns the conversation into a flirtatious one with a boy in the room. “For Derek’s sake, I made a joke about bandages, about looking like The Mummy...Mary [the nurse] realized she wasn’t getting anywhere with me” (54). The important part of this line is that Lucy, speaking in the childish persona that Grealy uses here, says that this fantasy is “for Derek’s sake,” a glaring hint to the reader that Lucy is not being honest with herself. She is directly, and immaturity, rejecting the information that Mary is trying to present her with. Grealy is trying to show that by avoiding the truth, Lucy can believe the truth does not exist: a youthful coping mechanism. In employing this mechanism, Lucy tries to gain control of the truth but is in fact denying herself that control by being too afraid to confront the situation.

The reclamation of voice that was lost in this scene, the regaining of control, only occurs several pages later when Lucy once again refuses to confront the seriousness of her illness. When a friend’s father whose wife died from cancer tries to prepare Lucy for the pains of
chemotherapy, she once again turns the serious conversation into a joke. After the man tells Lucy that her body will change and her hair might even be affected, Grealy shifts Lucy's voice to a more adult version through the narrator's confessional recognition of her foibles. Lucy reflects, "Having no idea what he was talking about and sensing something serious I'd rather not pursue, I made a joke to Evan about how my hair would turn green, my eyes purple" (63). The parallels between this episode and the previous one are strong. Both times, Lucy is approached by a minor character about a serious situation with her illness. Both times, Lucy uses humor to avoid the problem. Both times, Lucy gives the impression that the humor is a result of the presence of a boy—a seeming attempt to impress Derek and Evan. However, there is something unique in this instance. Lucy blatantly points out that she is "sensing something serious [she'd] rather not pursue." At this moment, Grealy is showing the reader an instance of her regaining control of the situation by recognizing her immaturity. In acknowledging the immaturity that brings about this loss of agency, we recognize her current mature perspective.

The narrator comes to a conclusion about both situations that shows her reformed opinion on the matter. She no longer supports her childish reaction to these two scenarios. Rather, she reflects, "This was the second time an adult had tried to approach me directly and seriously about my situation, and it was the second time I had turned it around; refused to tackle it" (63). Grealy now gives the speaker a more adult attitude to compensate for the speaker's lack of self-awareness during the chemotherapy scene and the scene with the nurse. The narrating voice has become fully self-punishing. This line is filled with guilt and shame as she states that "I turned it around" and "[I] refused to tackle it" (my emphasis added). The older Lucy is blaming herself for refusing "to tackle" the seriousness of her illness. This narration is mature in that it is
inwardly analytical. The reader goes from sympathizing with the child Lucy who cannot confront her illness to pitying the adult Lucy who centers the blame on herself.

Her shame-filled adult voice arises, also, when she goes to a doctor with her mother to complain about jaw pain. The pain would later be determined to be caused by cancer, but this doctor incorrectly labeled it a result of a sports injury. The doctor, speaking to the mother "condescendingly," ignores Lucy’s mother’s concerns over the continued pain (AF 25). The mother lashes out against the doctor’s arrogance, but Lucy refuses to support her mother or speak up and describe the large magnitude of her pain. She holds back, the reader presumes, because of her age. Grealy grants Lucy a more adult voice in this scene, and it is once again filled with embarrassment. Her mother looks to her for an affirmation of her concern. However, “unfortunately for my mother, I was still a typical nine-year-old, and I seized every opportunity to be embarrassed by her […] Not brave enough to actually speak up, I mentally rolled my eyes at each encounter between my mother and the doctor” (25). Here, Lucy’s adult voice recognizes that her childhood immaturity is hindering her voice, preventing any proclamation of authority on the issue of her own pain. The tone of the paragraph involves frustration and embarrassment, criticizing her lack of bravery and attributing her age to her inability to exert control over the situation. Overcoming this embarrassment reflects the adult voice that Grealy grants Lucy at times, a strategy that Grealy uses to reveal a more reflective, mature voice in the story. This strategy occurs as certain instances in the narrative, but the effect does not necessarily increase as the story progresses.

While the adult voice that Grealy gives to the narrator is self-loathing and depressing, it is, nevertheless, a new voice replacing the childish one. An adult, ashamed voice is replacing a child, humorous one. And while this is not an uplifting reclamation of voice, accepting guilt over
the situation is a method of reclaiming control and authority over the situation. The blame falls on her; the responsibility is given to her. Reclaiming control in order to express her voice and opinion is a result of her accepting responsibility for her earlier faults.

The theme of reclamation of voice is present in both of these narratives and is an important aspect of the genre in general. Arthur Frank tells the story of Irving Zola, a sociologist who suffered from polio at a young age and had a sudden self-realization when visiting a village in the Netherlands designated for disabled people. Zola discovers that “the last twenty years of his life represent ‘a continuing effort to reclaim what [he] had lost—the right to act sexy, get angry, be vulnerable, and have possibilities’” (Frank 122). While not all of these are prevalent in Bauby’s or Grealy’s narrative, the theme of recovering what is lost to illness is comparable. What Zola wants, in part, is agency, something that is vital for Bauby and Grealy.

Interestingly, one of the last pictures taken of Bauby is his witnessing of the publication of the book. Two days after the book was officially published, his heart gave out and he died from pneumonia. Valerie Raoul goes on to wonder, “Once the book had taken off, had the cocoon fulfilled its function? Is the book the butterfly?” (Raoul, et. al 188). While I don’t want to delve much into the spiritual realm, there exists this interesting possibility that the narrative fulfilled the function of the “cocoon,” releasing Bauby’s spirit into the world. And thus, the “cocoon,” Bauby’s body, no longer needed to continue living. Perhaps the knowledge that he had revealed himself to the world and had validated his worth was the basis for this fulfillment.

Regardless of the effects on Bauby the author, the illness narratives convey a message of reclaiming authority to their readers. As Frank puts it, in referring to literature in general, “the moral purpose of reading is to witness a change of character through suffering. In this witness the reader...affirms that change” (Frank 128). Both Bauby and Grealy suffer in their losses of
voice and agency. Grealy loses agency in the lack of respect she receives as a child and among other aspects of her immaturity. Bauby at times is not even treated like a person. His colleagues call him a vegetable and his ophthalmologist sews up his eyelid without warning as if he was a machine that needed fixing. In addition, both suffer from the inevitable disempowerment of the medical narratives. The narratives enable the characters to reveal their reclaiming of voice, which comes through in the form of agency, control, and authority.

The subject of this chapter addresses conversion similarly to chapter 1. Once again, there are conflicting impulses, an element of conversion narratives. Both authors must allude to, or even explicitly describe, their illnesses and the loss of voice within those illnesses in order to show their reclamation of voice. To reclaim something, it must first be lost, and both narratives simultaneously show both the losing and the conversion towards reclamation.

As Frank described above, there needs to be a “witness” to this change in literature, and the witnessing of this change is the focus of my next section. After seeing the theme of recovery in section 1 and the theme of reclamation of voice in section 2, there is still the uncertainty of who is supposed to witness this recovery and this reclamation.
Chapter 3

The Intended Audience

“People who write pathographies about their experience of illness are not just writing for themselves, they are addressing an audience—even if only an imagined, future audience.”
Anne Hunsaker Hawkins (123)

Chapter Introduction

In the above quotation, Anne Hunsaker Hawkins—a theorist on illness narratives—explains an illness-narrative author’s need of an audience as Arthur Frank’s claim suggested at the conclusion of the previous chapter. One unique aspect of this genre is that an audience is necessary; the authors are writing for others just as much as they are writing for themselves. Hawkins continues later on in her article on this subject, “It is […] the act of telling and the act of listening […] that creates the sense of human community needed to turn trauma victims into trauma survivors” (127). Through incorporating the works on trauma by Judith Herman and Robert J. Lifton, Hawkins offers the idea that the existence of the audience helps illness authors during their periods of recovery. Writing is a method of catharsis, a catharsis that is purgation for the traumatized author and that can incite overwhelming emotions in an audience. It is therapeutic for a writer but it requires an audience, and, in Greek theater, catharsis was the moment that an audience emotionally connected with a character in a tragedy. In a sense, this happens in illness narratives as well. The audiences, though, approach the stories with very distinctive perspectives.

There are several ways to read a narrative whether one has a personal connection to the story, sees use in reading the story, or simply finds the material interesting and engaging. This is especially true for illness narratives. There are three main audiences for reading pathographies:
medical professionals, fellow sufferers, and the unspecified.\textsuperscript{1} The previous two chapters were split into two sections: one on Bauby and one on Grealy. This chapter, on the other hand, will discuss each of these three perspectives in three different sections and will demonstrate how episodes in both Bauby’s and Grealy’s writings speak to each of these types of reader. This allows the focus of the chapter to be on the audiences and not on the texts. Rather, these texts are used to illuminate the most pertinent aspects of each perspective and demonstrate how the authors, specifically Bauby and Grealy, direct certain passages to different types of audiences.

The term ‘medical professionals’ describes anyone who works in healthcare and looks for constructive benefits in relation to their professions from illness narratives. The voice that speaks to them can help them improve their quality of care giving. Recognizing this phenomenon leads us to the question: are illness narrators trying to improve medical care? Do authors intend to teach medical professionals about the experience of the patient? In the cases of Bauby and Grealy, this outcome is definitively prevalent.

Fellow sufferers include people who suffer from the any illness as well as family members and friends who also have a personal connection to the story being told. While Bauby’s and Grealy’s illnesses are very rare and very specific, any person experiencing illness feels some form of disablement, confusion, and struggle in their lives. Taking on this perspective means that the reader sees the author as speaking on his or her behalf.

The final section of the chapter will analyze the unspecified reader who does not fall under either of the first two categories. This reader is the sympathizer, the unknowing, the outsider. The medical professionals and the fellow sufferers are a very limited audience, and illness narratives develop a wider range of readers. The narratives reach out to their audiences

\textsuperscript{1} “Fellow sufferer” is a term that I borrow from Arthur Frank while the “unspecified reader” is my own term.
and instill emotions in the readers in ways that allow any person to find enjoyment and value in the genre. Without being involved in medicine or experiencing illness like the authors have, unspecified readers still manage to connect with the stories and have a deep interest in reading them. I try to determine why this phenomenon occurs.

**The Medical Professionals**

Of course in any illness narrative, there is going to be a run-in or several run-ins with doctors, nurses, orderlies, etc. These interactions are more than quick conversations or necessary plot builders—they become vital elements of the story. Especially in *DBB* and *AF*, it is impossible to simply gloss over such moments and not reflect on the quality of healthcare taking place in the story.

Narratives are able to reach out specifically to medical professionals. Anne-Hunsaker Hawkins teaches a class to medical students and periodically has past patients come in as guest speakers to tell their stories of illness. Reflecting on the classes, Hawkins writes: “For the students it was a wonderful learning experience, one that strongly reinforced what I was trying to teach about the importance of understanding and empathizing with what it is like to be a patient” (113). Hawkins offers the idea that simply listening to someone’s experience with illness helps a doctor better empathize and understand patients in general. And, Bauby and Grealy both seem to make this a goal in their writings.

In a chapter titled, “Guardian Angel,” Bauby reflects on the healthcare staff very directly. He splits the hospital staff into “two kinds: the majority, who would not dream of leaving the room without first attempting to decipher my SOS messages; and the less conscientious minority, who make their getaway pretending not to notice my distress signals” (40). This passage cites a
common theme that arises in DBB when medical professionals appear. Frequently, Bauby defines ‘good’ hospital staff as those who simply pay attention to him as a person. Since he is motionless, voiceless, and helpless, he is easy to ignore. Those who don’t ignore him seemingly fall under the “majority” here, and this passage shows the reader the distinction between the superior majority’s treatment and the inferior minority’s.

The most caring person that Bauby encounters, his speech therapist, is the “Guarding Angel” in this chapter. The therapist, Sandrine, is the person who developed his coded communication system and helps him learn how to use it. The term is interesting since she is identified as a protector, a “guardian.” Since this chapter serves as a condemnation of medical professionals who ignore him and thus do not treat him as a full person, it is likely that Sandrine is a “guardian” because her system helps protect him from feeling inhuman. Connie Canam, a nurse-researcher, elaborates on this scene and specifically the difference between Sandrine and the unappreciative “minority.” She writes: “The contrast certainly points to the importance of health professionals attempting to understand the patient perspective” (Raoul, et. al 196).

Therefore, Bauby’s language and description of Sandrine within his narrative give medical professionals an opportunity to learn about the patient’s experience.

Arthur Kleinman, a professor of medical anthropology at Harvard University, explains why medical professionals should care about such moments in an illness narrative.

When the patient under examination disrobes to expose a body covered with the ugly scars of eczema or with the raw, red, flaking plaques of psoriasis, the practitioner should recognize that shame, hurt, anger, despair, or other constellations of feelings probably are present. As key ingredients of the illness
experience, these feelings are likely to affect the patient’s life experiences in
general. (43)

Medical professionals need to understand, according to Kleinman, that the emotions and feelings
associated with illnesses are significant components of the illness experience. And, thus, they are
significant components for physicians to understand when treating an illness. Both DBB and AF
are heavily laced with such moments that have the possibility of being valuable to medical
professionals.

Bauby’s self-descriptions within his narrative reflect Kleinman’s concern for medical
professionals to recognize the emotions associated with his condition. Early on, in a moment
discussed in chapter 1, Bauby explains that “improved resuscitation techniques have now
prolonged and refined the agony [associated with Locked-In-Syndrome]” (4). Machines, tubes,
and medical techniques are responsible for him being alive and continuing to live. Yet this is one
of the only mentions in the book of medical machines (other than of a wheelchair). And, this one
mention is negative; it is about techniques that have “prolonged agony.” He wants his image to
be distanced from the machines that are attached to him. They, undoubtedly, evoke a sense of
shame and dependence for Bauby. Rather than focusing on such machines and techniques that
treat the physical symptoms of his illness, Bauby chooses to focus on himself as an individual,
on his emotions and personality. As Kleinman discussed above, the recognition and
consciousness of such emotions is important for medical professions in understanding the illness
experience.

Grealy also has run-ins with doctors that seem to be a social statement about proper
medical care. Her experiences in AF indicate her desire to be treated like an adult. As a child,
Lucy often feels that she is being talked down to whenever in the presence of a medical
professional. When meeting with Dr. Conley, her plastic surgeon, Grealy writes: “He sat down and spoke to me in the tone of someone speaking to a child, which served to both instantly destroy and strangely build the trust in him I had felt only moments before” (153). At this point in the story, Lucy is an adolescent nearing high school age. The most obvious moral of this passage is that patients do not want to feel inferior to the knowledgeable doctors. Bauby calls the ophthalmologist in the scene discussed above as “arrogant” and “brusque” (54). These are the same traits of Dr. Conley that anger Lucy in this scene. Surprisingly, the arrogance also leads to Lucy trusting Dr. Conley, likely because it reflects confidence. Grealy is declaring that a medical professional needs to achieve this balance. She is presenting her opinion on healthcare, an opinion developed through illness.

Grealy’s unique age during her illness also brings up unique situations for doctors to consider in the book. When first seeing a doctor about her cancer, her parents accompany her to the visit. Lucy thinks to herself, “I wasn’t used to seeing my parents defer to people in positions of authority” (31). This passage can be interpreted as useful for medical professionals, making them aware of the confusions for children in this setting, making them conscious of the “position of authority” that they reside in.

Hawkins writes that some illness narratives aim to create social change in the medical field. She recognizes that occasional pathographies are written “with the ultimate aim of bringing about institutional and cultural change. Many authors are critical of the medical establishment” (Hawkins 125). While I think that neither DBB nor AF have the “ultimate aim” of changing the medical institution, there are several elements of medical criticism in the narratives that can be constructive for a medical-professional audience. The style of some passages gives the impression that they are intended for such an audience. However, this is not the “ultimate” or the
sole aim of these two illness narratives. There are also moments that are intended for fellow
sufferers and even moments for readers who have no direct connection to the illnesses.

Fellow Sufferers

Fellow sufferers read illness narratives in a completely different light than medical
professionals. This audience includes someone with the narrator’s specific medical condition,
someone who is suffering from a relatable condition, or a friend of someone who is suffering. In
each case, the fellow sufferer empathizes with illness narratives and is able to identify with
moments in the narrative that resemble one’s own life. However, the authors of illness narratives
do not only connect with these people in their writings, but also write on the behalf of the fellow
sufferers.

James Overboe, a sociologist who is disabled and who admits to being called “a
vegetable” as a child, reflects on *DBB* from his unique perspective as a disabled man. He writes,
“The diving-bell, for me, does not represent Bauby’s imprisonment by LIS [Locked-In
Syndrome] but rather the oppressive practices of those who usually privilege an able-bodied
perspective” (Raoul, et. al 193). Overboe’s definition of “the diving-bell,” a central part of
Bauby’s narrative, is entirely different than my own description of it in chapter 2 and than the
common description of the metaphor. As a disabled person himself, Overboe sees the story from
a different angle that causes him to be more sensitive to the oppression of disabled people. He
believes that the diving-bell is a function of society’s privileging of able-bodied people rather
than a depressing “imprisonment” that is the result of a tragic condition. In referring to the
average members of society, Overboe says: “They see the problems of lack of communication, of
lesser embodiment and absence of selfhood, as residing with Bauby as a result of LIS. In
contrast, I see the problem as lying in such readers’ inability to understand his attempts at
communication, their failure to appreciate his embodiment, and finally their refusal to recognize his selfhood” (193). For Overboe, the problem lies with the readers and doctors and nurses who cannot understand Bauby rather than with the disability. Society creates the diving-bell, not the disability.

Overboe concludes by seeing Bauby as a messenger for people like him. Overboe says of Bauby, “the reaffirmation of his presence may help open the restrictive cocoon of what constitutes ableism, which has a negative impact on the interaction between most disabled and nondisabled people” (193). Overboe sees the social impacts of Bauby’s work, that his book may lead to greater social questions in defining ‘able’ and social progress in the treatment of “nondisabled people.” Being called a vegetable when he was a child and then reading a chapter in DBB titled “Vegetable,” Overboe cannot read the book without connecting his own life to the story and relating to Bauby’s experience.

Bauby, in a sense, becomes a spokesperson for disabled people. Frank speaks about this subject, saying: “An ethic of solidarity and commitment is expressed when the storyteller offers his voice to others, not to speak for them, but to speak with them as a fellow-sufferer who, for whatever reasons of talent or opportunity, has a chance to speak while others do not” (Frank 132). Bauby has talent and experience from editing a major fashion magazine. This position in society also likely helped elevate his opportunity to write such a book. With his talent and his opportunity, he is, according to Frank, obliged to speak for others who cannot speak. Bauby writes both for himself and as a spokesperson for the fellow sufferers.

The issue of being a spokesperson is particularly interesting for Bauby, a man who is literally unable to speak. His ability to represent a group of people is a way for Bauby to assert his strength, a form of validation. Overboe even says: “[Bauby] validates his presence through
his attempts to engage others” (192). By addressing an audience, Bauby feels validation, which I discussed in chapter 2 of this thesis. However, Overboe does not make the connection between this validation and being a spokesperson. Bauby, figuratively, is reclaiming a “voice” by having fellow sufferers as an audience because he writes for them on their behalf. Not only does he reclaim a voice for himself through his self-validation, but he also claims a voice for various others who are unable to speak out about their illnesses.

In addition to being spokespeople, illness narrative authors invoke relatedness between the reader and the narrator with the ability to spark a memory or empathy from a fellow sufferer. For example, both AF and DBB discuss visitors and the difficulty associated with the interactions between patients and visitors. The reason the visitor scenes best fit for this section is because they include both the patient and the patient’s friends and family, which means the scenes exclusively include people defined as fellow sufferers. Grealy shows Lucy slowly develop her opinions towards visitors since she is a child in the story and her character progresses. Lucy says, “Suddenly I understood the term visiting. I was in one place, they were in another, and they were only pausing” (AF 58). Lucy feels disconnected from her visitors; she is permanently experiencing her illness while visitors only have to pause and experience it while they are with her. Any fellow sufferer, relative or patient, would be able to at least understand Lucy’s words and possibly relate to them.

Bauby speaks about visitors too, but with a feeling of superiority. He writes: “Because of nervousness, impatience, or obtuseness, performances vary in the handling of the code” (DBB 20). The “code” is the unique form of communication that Bauby uses by blinking his left eye at letters placed in front of him. His feeling of superiority is noticed by his calmness in this statement and the knowledge he evokes in this statement. He gives the impression that he knows
everything going through the mind of his visitors but that they often cannot understand him. They struggle to communicate with him but he recognizes their inner emotions of "nervousness, impatient, or obtuseness." This feeling of superiority has been demonstrated in this thesis as being exemplary of Bauby's method of overcoming illness. His narrative allows him to assert himself and gain that superior control over his situation. This is how he views his recovery and how he measures his agency.

His calmness and confidence also ease the tension for the reader as the reader visits Bauby through the words of this book. Readers feel comfortable visiting Bauby's private world because of the manner in which he writes. This style of writing can also ease the tension for fellow sufferers in their lives. Patients, especially, have the opportunity to relate to that desire to be strong in difficult situations such as when vulnerable relatives and friends come to visit.

Some moments in the narratives can be interpreted as for fellow sufferers or for the unspecified reader. When Lucy's Dad awkwardly exits the chemotherapy session to get the car well before the injections are finished, Lucy reflects, "Perhaps in part he was embarrassed to see his daughter half naked, but I knew that he did not want to see me suffer" (84). If the reader interprets this literally, then it seems that Lucy understands the hidden kindness that is behind her Dad's awkward, rude decision. For a fellow sufferer, it can be very comforting to witness another patient find the good in a difficult situation. But another interpretation makes the passage seem that Lucy is lying to herself in order to get over the discomfort of seeing her father so vulnerable. Her father does not have the strength to witness something that she is forced to have the strength to go through. This apparently deeply affects Lucy as a daughter. Therefore, if you read this statement literally, it can be intended for a fellow sufferer. But if you read it as a child's coping mechanism, then it is intended for the unspecified reader because it lets that reader enter a
world that was formally unknown to such an audience. It provides readers insight into a part of the human condition which the readers are unable to get through their own life experiences.

The Unspecified Reader

The interest in these stories for medical professionals and for fellow sufferers is clearer than the interest of audience members who do not fit under these categories. Based on my readings of *DBB* and *AF*, I see the authors opening a door to unspecified readers that is normally shut. Bauby and Grealy publicize the privacies of their lives and give the unspecified readers insight into the illness experience. Arthur Kleinman’s theory, which bears on the interest of the unspecified reader, is that illness narratives have the ability to represent something much greater than overcoming illness. He writes: “To maintain one’s aspirations in the face of grave adversity, to work hard to contend successfully with the daily assault of an impaired body on a robust spirit, to be victorious over the long course of losses and threats that constitute disability—these are lessons for us all, examples of what is best in our shared humanity” (137). Kleinman sees a deeper meaning in illness experiences that extends beyond medical professionals and fellow sufferers. This section will look at moments where the author lets the reader witness something very specific to his or her illness experience since these are the moments that seem most directed to readers who are not as familiar with illness as medical professionals and fellow sufferers.

By narrating scenes that are explicitly private moments of their lives, Bauby and Grealy show unspecified readers something they would never witness without reading these stories. While being wheeled through Paris and recognizing the sites and sounds around him, Bauby becomes very sentimental. His eyes start to water, and he tells the reader, “I shed a few tears as we passed the corner café where I used to drop in for a bite. I can weep quite discreetly. People
think my eye is watering" (78). In the story, the people guiding Bauby around the city and even his family are unaware that he is actually crying and that his eye is not involuntarily watering. However, he drags the reader into his perspective. He tells the reader a secret about his illness experience: his ability to hide his tears. This passage seems directed at an unspecified reader who gains knowledge that is privy only to those who experience illness and disability first-hand. We feel confided in. We are able to share an intimate moment with Bauby. More so, the passage addresses issues that extend beyond illness and bring about questions of courage, vulnerability, and strength. It causes a reader to wonder why he has to hide his tears. Why does he speak gratefully about being able to "weep quite discreetly"? Bauby’s words once again reveal a very brave and resolute man who subtly cries in order to try and hide it from the people he is walking with. The insight provided to the unspecified reader allows these questions to be asked.

Grealy’s moments of privacy revealed in her narrative tend to evoke a feeling of sympathy. When Lucy is supposed to take her high-school yearbook photograph, she skips school over the embarrassment of her appearance. Afterwards, she says: "I threw away all the subsequent notices warning that unless I attended the makeup shoot, my photo would not appear in the yearbook" (190). The tone of this passage indicates that both her school and her parents were unaware of her actions. Grealy is letting the reader observe a moment in her life that she experienced alone and that she experienced because of her illness. The significance of this passage is that, presumably, nearly everyone reading this story has gone to high school and taken a yearbook photograph. The high-school yearbook becomes a symbol of a person’s past and a protector of memories. Lucy is metaphorically ridding herself of her memories of high school and of her face in high school. The average reader can sympathize with the moment in the narrative because it takes a common, relatable moment in the reader’s life and shows how that
moment was altered for Lucy because of her illness. The reader truly gets insight into illness because he or she is able to see the uncanniness of Lucy’s yearbook experience, a very recognizable circumstance.

Moments of sympathy can also be moments of guilt for particular unspecified readers. While they cannot connect with the ill narrator because they lack similar experience with illness, they may connect with other characters in the story. Lucy goes into great detail about the boys in school that tease her because of her physical appearance. Lucy tells the reader, “The pain these children brought with their stares engulfed every other pain in my life” (7). Readers who are not medical professionals or fellow sufferers still likely experienced, witnessed, or caused teasing at one point in their lives. Furthermore, Lucy explicitly tells us that the pain from teasing “engulfed every other pain in my life,” meaning that the physical pains of cancer, surgery, and chemotherapy were forgotten because of the power of torment from these children. Therefore, when the narrative goes into great detail in other chapters about the physical pains of Lucy’s childhood, this statement intensifies and the emotions of sympathy, empathy, and guilt that may develop in an unspecified reader grow stronger. The words can become, in a way, didactic for the unspecified reader.

Passages like this one allow the book to reach beyond the illness experience and connect to greater meanings, as Kleinman proposes in the quote with which my thesis began. It reads: “Meaning is inescapable: that is to say, illness always has meaning. The experience when ill need not be self-defeating; it can be—even if it often isn’t—an occasion for growth, a point of departure for something deeper and finer, a model of and for what is good” (144). Grealy’s passage, in following with Kleinman’s proposal, can cause readers to look inward at personal faults or judgments related to people with medical conditions. At the very least, it causes readers
to evaluate their own views on what exactly constitutes beauty. Ann Patchett, Lucy Grealy’s best
friend and colleague in creative writing, wrote about Grealy’s opinion of the book, “[Lucy]
wanted [her readers] to learn not only about the facts but also about their abstraction, to think
beyond what we already know” (Patchett 233). The incidents of teasing and the example of the
yearbook photograph allow this goal to be achieved. In order for the readers to think beyond the
facts, they must be dragged into the material and feel a part of the story. These examples create
relatedness for the unspecified, seemingly unrelated reader.

The narratives also pull the unspecified readers into the stories by using narrative
techniques to make readers more aware of the symptoms. Bauby, while sitting in bed one
morning, tells the reader, “I am [...] practicing sliding my tongue towards the rear of my palate
in order to provoke a swallowing reaction” (12). A reader who is ignorant of locked-in-syndrome
immediately becomes conscious of his or her ability to provoke a swallowing reaction. In fact,
when I read this passage, I tested my own swallowing reaction by pushing my tongue towards
the back of my mouth. Bauby’s writing forces the reader to become aware of his struggles and
inabilities. A task that the reader would normally take for granted requires daily “practice” for
Bauby to ever hope to achieve. Once the average reader is able to step into Bauby’s world and
reach that understanding of what it is like to have locked-in-syndrome, even if for a brief instant,
the reader can better start to connect to the illness experience and better appreciate the significant
moments of the illness narrative.

Whether a reader connects with the story as a fellow sufferer or healthcare provider, feels
sympathy for the author, or simply learns more about an illness, the audience is able to gain
insight into the importance of the experience associated with illness. Furthermore, as Kleinman
points out, there is the potential to connect this insight to more general moments in people’s lives
that involve courage, determination, and growth. Kleinman furthers his theory, saying, "The study of the process by which meaning is created in illness brings us into the everyday reality of individuals like ourselves, who must deal with the exigent life circumstances created by suffering, disability, difficult loss, and the threat of death...Illness narrative edify us about how life problems are created, controlled, made meaningful" (xiii). Both DBB and AF do demonstrate that the difficulty in dealing with illness can encompass greater meaning than simply the illness itself. They allow the average reader to address larger issues in life that exist in all of our experiences whether we can connect with the actual illness or not. Witnessing the struggle within an illness narrative thus garners interest in an audience and, occasionally, can even inspire.
Conclusion

This thesis’ goal was, through the analysis of two specific texts, to explore the relationship between writing and illness and see how that relationship connects to a larger issue of illness experience. Jean-Dominique Bauby and Lucy Grealy show that illness narratives provide a venue for understanding the complexity of illness, especially when, in both of these cases, the literal and physical illness itself is not the main source of pain. Often, patients do not simply get sick and get well without a more elaborate experience behind those processes.

The recovery from this more abstract source of pain brings about questions about health. As it turns out, the conditions of one’s recovery depends on one’s personality, behavior, and life experiences. The genre of pathographies leads to insight about recovery, agency, beauty, and health, questions which arise because of the manner in which the pathographies are written. By looking at the specific language, narrative techniques, and content choices of illness narratives, we are able to learn more about illness and health. In other words, a literary perspective can help enlighten a medical and a social perspective.

While AF and DBB guided my analysis in reaching conclusions about recovery, agency, and audience within illness writings, there are many other types of memoirs within the genre that would be worth looking at. The next step from this thesis is to examine stories with more common illnesses than jaw cancer and locked-in-syndrome like allergies or paraplegia. In addition, it is worth looking at terminal patients who write illness narratives with the knowledge of death’s proximity. Another interesting set of illness narratives deal with people who contract labels and stigmas along with their specific diseases. Authors of H.I.V. autobiographies and autobiographers with type 2 Diabetes have diseases that are tightly linked with social stigmas, blame, guilt, and social change. The complexity of illness writing regarding H.I.V. or A.I.D.S. in
so intricate with issues of sexual orientation, historical relevance, and labeling that it deserves an analysis completely on its own.

In addition to these other physical illnesses, there is mental illness, an issue that I intentionally avoided with during this project. Mental illness is perceived by the public—and, in my opinion, rightfully so—as a completely separate entity than physical ailments or diseases. The ambiguity regarding such disorders in their causes, proper treatments, and even in their diagnoses in much greater than the ambiguity—at least in modern medicine at the time this thesis was written—associated with more physical problems. Like the diseases mentioned above that are associated with stigmas and labels, mental disorder narratives would also require a separate and detailed exploration, rather than lumping them in with general conclusions about illness writing.

All of these different sub-genres of illness narratives could help strengthen or question the conclusions from this thesis. It would be interesting to see what defines recovery for different illnesses than jaw cancer or locked-in-syndrome. It would be interesting to see if the issue of agency even arises in certain pathographies. It would be interesting to see how certain ill writers address their audiences, whether some push more for social change within the medical field or social change throughout all of society by primarily being a spokesperson for a disease. In terms of Lucy Grealy and Jean-Dominique Bauby, recovery, agency, and audience play a vital part in their remarkable stories about struggle, courage, and healing.
Works Consulted


