

In her book *Illness as Narrative*, Ann Jurecic surmises the work of psychologist James E. Pennebaker as such: ‘Although he does not promise that writing is cure-all, his research demonstrates that the practice of composing provides a means for organising an understanding of one’s life and self, and for gaining insight into uncertainty and the unknown.’ (Jurecic 2012: 11) ‘Uncertainty and the unknown’ are feelings that commonly accompany medical treatment. Pathographies, memoirs, illness narratives, autopathographies; all are forms of the same literary genre which afford the writer, whether the patient or a close companion to the patient, a space in which that uncertainty and unknowing can be explored. Jean-Dominique Bauby’s *The Diving-Bell and the Butterfly* (1997) and Hilary Mantel’s *Giving Up the Ghost* (2003) both use autopathography to explore their identity in relation to their disability or illness. As each does, they align with Pennebaker’s work, proving that in writing an autopathography, an understanding and clarity of one’s identity can be obtained. This essay will explore Bauby and Mantel’s experience of social attitudes towards disability and illness and how these attitudes are embedded in medical practices, before considering their resistance and response to these experiences. In doing so, the value of the autopathography in providing a space for authors to explore, assert, and *reassert* their sense of self during illness becomes clear.

Anne Hunsaker Hawkin’s *Reconstructing Illness: Studies in Pathography* provides a comprehensive look at the various myths, attitudes and approaches that are taken to medical narratives. Fundamentally, her focus is on the power of the pathography to give voice to the patient, in turn establishing a ‘movement towards a patient-centred medicine.’ (Hawkins 1999: xii) Pathographies document the personal experience of a patient’s illness, the ‘internal’ account, however they are commonly taken and applied to the ‘external’ world which concerns the broader conversation surrounding medicine. Their construction typically comes from a need or desire to grasp one’s identity amidst trauma, for an individual ‘to orient themselves in the world of sickness’ (2). Bauby and Mantel’s memoirs are examples of autopathographies; texts in which the author and patient present an account of their illness experience. In a culture in which medical authority is centralised to professionals, Bauby and Mantel use their voice *reassert* (or *assert*) their identity amidst dominant medical voices. Though suffering vastly differing illness experiences (Bauby a sudden stroke which leads to his having locked-in syndrome; Mantel suffering a lifelong illness, continually misdiagnosed and mistreated), each similarly become subject to society’s obstacles: attitudes, expectations, standards and prejudices which plague illness and disability and associate them with

weakness and, often, failure. In using literature to assert themselves, these surface level prejudices are, at least to a degree, removed. There is no physical representation of the body, their 'diving-bell', and rather the focus is on the mind, their 'butterflies'. As Couser surmises, there is a 'redemptive shifting of emphasis from the body to the mind' in their written accounts of illness experience, with it serving as a 'self-rehabilitation' which 'involves in large part redefining the self as more a function of mind and spirit than of the flesh.' (Couser 1997: 185) Despite the vast difference between their illness experience, Mantel and Bauby similarly use autopathography explore and establish their identity.

Left with only the ability to blink one eye, Bauby finds his pre-stroke identity 'fading away. Slowly but surely... My old life burns within me, but more and more of it is reduced to the ashes of memory.' (Bauby 2008: 85) While his family ask if he is still there, Bauby himself is uncertain: 'I have to admit that at times I do not know anymore.' (48) While Bauby feels himself fading, he refuses to conform to the belief that he is only a 'vegetable' (90) whose whole personal identity is lost by physical change. In asserting his intellect, Bauby creates a legacy for his pre-stroke identity while also exploring and understanding the transformation his identity has undertaken. *The Diving-Bell and the Butterfly* permits for Bauby 'a kind of neutral space for self-presentation and the renegotiation of status.' (Couser 1997: 182) For the sake of himself and his family around him, he uses his 'thunderous inner voice' (Bauby 2008: 118), as a result, reasserting his identity and creating a legacy for both his pre- and post-stroke self.

In contrast to Bauby, Mantel's memoir is not a reassertion but rather an attempt to assert for the first time an identity never claimed. Subject to late twentieth century gender ideals, medical practices and social values, Mantel's identity was not formed by her. Despite her determination 'to distinguish myself in my generation' (Mantel 2013: 94), Mantel 'for a long time... felt someone else was writing my life... The book of me was being written by other people: by my parents, by the child I once was, and by my own unborn children' (60). In a diary entry published seven years after *Giving Up the Ghost*, Mantel writes further on her using writing to establish identity:

'Imagine you were creating all your experience by writing it into being, but were forced to write with the wrong hand; you would make up for the slow awkwardness by condensing phrases, like a poet. In the same way, my life compresses into a metaphor.' (Mantel 2010: para. 5)

Mantel's autopathography frequently suggests this 'creating' of experience. Hawkins vitally raises the point that writing from memory risks misrepresenting the actual experience (Hawkins 1999: 15). There is the potential for facts to be 'dropped', or an experience to be '[endowed] with a significance that was probably only latent in the original experience.' (15) However, Mantel's autopathography does not endeavour to present a perfect factual account of what led her to be the woman she is as she writes *Giving Up the Ghost*. Rather it sees Mantel explore, probe, and interpret her version of her life to create her own identity for the first time. 'When you were a child you had to create yourself from whatever was to hand. You had to construct yourself and make yourself a person.' (Mantel 2013: 225) In *Giving Up the Ghost*, Mantel is creating this self that she was unable to as a child. She is giving up the ghosts that have 'formed' an identity not true, honest, or even merited to her. Just as Bauby asserts his voice in his autopathography as a means of escaping the diving-bell restricting his body, Mantel writes hers to escape a similar diving-bell, one which has weighed down her body not only is physicality, but in spirit also. Hawkins states that 'pathography can also be seen as the final stage in the process of formulation, completely the bridge between the suffering self and the outside world by an overt act of communication.' (Hawkins 1999: 25) Bauby and Mantel assert their sense of the self, whether for the first time in their life or otherwise, by reimagining their existence, and then writing it down as a conclusive record of who they are in actuality.

As established, throughout *The Diving-Bell and the Butterfly*, Bauby attempts to reassert his identity, using writing as a means of doing so. However, this need to reassert himself comes as a response to society's wider attitudes to disability and to the mixed levels of care, patience and support experienced in medical institutions. Pathographies, as Hawkins outlines, appear to have emerged originally over the course of the 20<sup>th</sup> century, and as a result, numerous changes and developments can be readily seen (5). Writing contemporaneously to the publication of *The Diving Bell and the Butterfly*, Hawkins addresses the 'cultural discontent with traditional medicine', as expressed in pathographies either through anger at depersonalized medical treatments or with a focus on alternative therapies (5). While Bauby's narrative does not concern alternative medicine, nor read as angry *at* the medical institutions he is treated by (on the contrary, he frequently thanks and praises them), his experience illustrates the changeable nature of medical treatment, often excellent, but at times depersonalised and not patient focused. Whilst pathographies set out to afford patients a voice and encourage a more sympathetic medical attitude than previously

adopted, Bauby illustrates within his autopathography just why this is essential. Bauby's case of locked-in syndrome left him with minimal movement, though more than is typical: 'I am perverse enough to be able to swivel my head, which is not supposed to be part of any clinical picture.' (Bauby 2008: 19) The 'clinical picture' Bauby outlines is one all too familiar amongst those suffering illnesses. The sterile, cold and impersonal image of illness is one typical of medicine and medical literature such as case histories. Outside of autopathographies, the dominant perception of illness is the medical one, rather than the personal. Bauby is 'perverse' for being left with the smallest fragment of movement. Rather than this being deemed as hopeful for his case or unique to his diagnosis, it casts him outside the standardised image of locked-in syndrome. This depersonalised diagnosis aligns with his presentation of medical institutions. The hospital he is treated in is frequently described in military barrack-like terms: a vast brick fortress like building, originally intended for use in the Second World War, 'a battalion of cripples form the bulk of the inmates' (39). Bauby's description of the building and patients conveys the institutionalised nature of medicine that autopathographies have come to encourage against. This is further reinforced in Bauby's depiction of the hospital staff. Though many are caring, patient and endeavour to communicate with him - his speech therapist Sandrine, his 'Guardian Angel' (47) who 'at once sends all gloomy thoughts packing' (48), with both her cheerful temperament and her affording him a system of communication – there are members of staff who work with functionality and little consideration for the patient in question. This 'less conscientious minority... pretending not to notice my distress signals' (48) are representations of the depersonalised medical approach which non-patient driven medical narratives often depict. This treatment of patients illustrates the necessity for autopathographies in asserting a more compassionate, patient centred medical service. When he is saved from death but diagnosed with locked-in syndrome, 'the sufferer is the last to hear the good news.' (12) Despite it being his body in question, the news is passed around many others, medical and otherwise, before coming to Bauby. Immediately upon illness, the medical institution's voice overpowers his and as a result, his agency and freedom, are removed. With an inability to use his voice and communicative success only achieved when patience and cooperation is issued on the part of the staff, Bauby's identity comes to fade. Not only does his medical condition weigh him down, but the treatment and attitudes of those around him, the anonymised 'white coats' (17) he refers to, do so also. While the medical staff celebrate his diagnosis, Bauby feels it has 'the ring of a life-sentence' (17), and now sees himself as one of 'those castaways on the shores of loneliness.' (36) In his essay, John Wiltshire states that 'patients write memoirs... as an act of

protest, as a recall to the fact that one is not only a body, and to rescue the whole experience of illness and medicalisation from the narrower definitions of the clinic.’ (Wiltshire 2000: 412) Just as the medical professionals and hospital environment reduce Bauby to one patient amidst many diagnosed, labelled and neatly categorised, Bauby is forced to negotiate how to reassert his identity outside of his diagnosis when he cannot do so by physical or oral assertion.

Bauby not only has to reassert his identity from the medical voice however, but further from the social attitudes toward disability that threaten to redefine him. Back in Paris, those who talk about his condition render him ‘a complete vegetable’ (Bauby 2008: 90). Gossip and rumours become, for others, facts: ‘The tone of voice left no doubt that henceforth I belonged on a vegetable stall and not to the human race.’ (90) Without a literal voice to defend himself, Bauby’s identity becomes overpowered by these renderings. His identity not only passively ‘fades’, but in cosmopolitan social circles is forced away from him. When on the beach outside the medical facility, this image of self as a disability rather than as a man is further reinforced for Bauby. He observes that ‘No one pays me any real attention. Wheelchairs are as commonplace in Berck as Ferraris in Monte Carlo, and poor dislocated wheezing devils like me are everywhere.’ (94) As he observes this, he listens to a conversation between his old friend and Claude, in essence his ghost writer. As Claude is told of Bauby’s character, he realises that ‘life is divided between those who knew me before and all the others.’ (94) Bauby illustrates that just as the outside world sees him as only a disabled man in a wheelchair, that is what he is coming to believe himself to be. Without a voice or physical movement, he feels vulnerable to the rumours and storytelling, whether malicious or well-intentioned, of others. Couser explores the differences between illness and disability when writing pathographies, with the vital difference being illness as temporary, but disability as permanent. However, he also highlights the fact that where ‘most illnesses are not stigmatic, disability is’ (Couser 1997: 177) Bauby thus not only must reassert his identity against medical attitudes toward the patient, but further to social stigma against disability. It is through writing, intellect and autopathography that he refutes stigma and reasserts his voice for himself. Rather than it being the Parisian acquaintances ‘tone of voice’ that endures, Bauby makes steps ‘to prove that my IQ was still higher than a turnip’s’ (Bauby 2008: 90) and to prove that while his physical identity may be drastically changed, his mental identity formed of his spirit, values, emotional capacity, memories and intelligence remains.

Over the course of her life, Mantel's illness experience similarly poses obstacles to her establishment of identity. While Bauby attempts to *reassert* his identity, Mantel is asserting hers for the first time. Her lack of hold over her identity is rooted in the abundance of ghosts that haunt her: deceased family members; unborn children; versions of her life that could have been. *Giving Up the Ghost* navigates and explores these ghosts, permitting Mantel the space to, ultimately, give them up. Much of Mantel's unclaimed sense of self (of which the ghosts remind her constantly) stems from her long misdiagnosis and mistreatment of endometriosis. Embedded in this medical treatment Mantel received were gendered attitudes. In considering her experience of girlhood and womanhood in relation to her illness, the obstacles that have restricted Mantel from asserting her sense of self become evident. In recounting her childhood, Mantel's writing is laden with gender norms of her mid-20<sup>th</sup> century upbringing: women would not visit the local pub (Mantel 2013: 233), 'men want sons' (130), 'a woman never did anything, you observed at once' (90). Her whole upbringing was embedded with these gendered attitudes. Amidst this, Mantel desperately wanted to be a boy. Her narrative frequently returns to the phrase 'I am waiting to change into a boy. When I am four this will occur.' (40) This point is referred to as Mantel reasserts her 'waiting' before admitting that it will not happen: 'Girl could change to boy: though this has not happened to me, and I knew now it never would.' (97) Mantel's childhood is plagued with her desire to be something different, a version of herself – strong, independent, empowered – that she was not permitted or expected to be. There is a sense of loss for this boyhood: 'I have lost the warrior's body I had before the fever' (57), 'my bullet-like presence, my solidity, has vanished.' (57) The ghosts of Mantel's life begin with her gendered experience. One of the first ghosts she lives with is this boy she longed to be but could not be. Throughout her life, and her illness, her gender comes to dictate her experience and in turn, her identity. Just as Mantel could not escape the girl's body of her childhood, she cannot escape the woman's body of adulthood: she becomes her own 'diving-bell', to use Bauby's terms. Mantel's diagnosis in adulthood is stress, 'a female complaint' caused by 'over-ambition' (174). Mantel's treatments plague her more, with anti-depressants which rob her of her eye sight and pills which cause her drastic mood swings. Now in adulthood, Mantel's gender experience further restricts her. Her treatment causes her to become the misdiagnosis: mad. As a result, she fails to study or work. In childhood, social attitudes on gender robbed Mantel of the identity she longed to have. In adulthood, these same gendered attitudes, now embedded in medical practice, afford her a new identity, but a false one, which pits her against the ambitious and strong self she truly sought to be. In turning to self-diagnosis and,

much like Bauby, intellect and writing, Mantel establishes a sense of self she never had. As Robert Kusek argues, she is able to '[investigate] cultural construction and, crucially, offers an attempt to re-claim the writer's alienated body.' (Kusek 2014: 181)

Hawkins has referred to the pathography as 'our modern adventure story.' (Hawkins 1999: 1) It permits the patient to be 'transported out of the familiar everyday world', escaping the hospital bed or the physical pain (1). Bauby and Mantel's autopathographies embrace 'adventure' in a sense as they put their imaginative thoughts down on paper, exploring the versions of themselves they were or hope to be. The transportation Hawkins writes of permits an escape from the pain and suffering of disability and illness. However, as a further result, it permits them authority over their own identity. Their autopathography becomes the guidebook to their identity. Built off their experience and intellect, both texts assure that their identity is not lost to salacious gossip, clinical pictures, misdiagnosis or social prejudices. While Couser argues that the 'autobiographer does not have the same latitude as the novelist... in constructing a world' (Couser 1997: 182), what Bauby and Mantel have instead is authority to assert their world. Throughout *The Diving-Bell and the Butterfly*, Bauby combines his pre-stroke memories with imagination. In reminiscing over travel, good food and fond family memories, he 'creates himself, waving a personality erected upon an edifice of recollection.' (Dudzinski 2001: 34) It is Bauby's mind that permits him escape from his disability: 'my cocoon becomes less oppressive, and my mind takes flight like a butterfly.' (Bauby 2008: 13) He combines memories ('I have stored away enough pictures smells and sensations' (111)) with imagination ('my roving mind was busy with a thousand projects: a novel, travel, a play, marketing a fruit cocktail of my own invention.' (15)) In doing so, Bauby permits himself freedom from the medical institutions and social attitudes toward the disability that his physical change has seen him 'become'. It serves as an escape, not *from* himself, but rather *to* himself. Throughout his autopathography, he retains his dark humour: 'When I began a diet a week before my stroke I never dreamed of such a dramatic result.' (23) In retaining this honesty, humour and, at time, scathing critique of others, there is an avoidance of self-editing to create a perfect image of himself. While Bauby changes physically, he retains the same mental identity that he always had. Bauby *reasserts* himself with the identity he had firmly established pre-stroke. This is further permitted to him through his literary control. He writes newsletters to his family and friends, '*samizdat* bulletins' (89) (the banned nature of 'samizdat' further illustrating his physical imprisonment, in body and medical institution) which allows him to transcend the impatience or

awkwardness others experience when communicating with him. This permits authority over his voice and the space to communicate free of misunderstanding. Writing his autopathography extends this assertion beyond his social circle and on to the wider world, allowing *The Diving-Bell and the Butterfly* to be read amongst other works which give representation to disabled or ill persons whose voices are presumed redundant once their body is weakened. Bauby describes the words he writes as ‘extracted from the void’ (138). Not simply a memoir or diary, Bauby carefully crafted each sentence of his work, reaching in to ‘the void’, deep in to his mind and spirit. As Denise Dudzinski argues, Bauby’s text serves as the ‘final expression of himself.’ (Dudzinski 2001: 34) In the process of writing, Bauby not only reasserts his identity, but also serves as a representative against the dismissal of the disabled voice. Further, he undergoes a transformative process. By the conclusion of *The Diving-Bell and the Butterfly*, Bauby admits to himself that he has begun a new life (137), moving beyond ‘regret for a vanished past, and... remorse for lost opportunities’ (102) in to an acceptance, with ‘a heart that is almost light’ (138). In accepting his permanent condition, writing carefully and purposefully and reasserting his identity, Bauby permits himself a transformative sense of self. No longer is he a diving-bell *or* a butterfly, but he is a conflation of the two, a new version of himself post-stroke that retains his lifelong identity, but with a newfound, although uncontrollably altered, clarity and purpose.

*Giving Up the Ghost* similarly affords Mantel space to assert her identity. Throughout the text, Mantel remains clear on her aim: ‘I began this writing in an attempt to seize the copyright in myself.’ (Mantel 2013: 60) In asserting her literary authority over her text, Mantel simultaneously asserts authority over her identity. In its structure, *Giving Up the Ghost* reflects the therapeutic, explorational approach Mantel is forced to take in recounting her life. Childhood memories are interrupted with reflections on why she is writing a memoir, her childhood interspersed with the childhoods of distant ancestors and comments such as ‘I like to get close to people who are thinking’ (39) read not only as a fond childhood memory but rather a lifelong interest. By establishing this convoluted narrative, a sense of clarity is absent for the reader which reflects that absence for Mantel. *Giving Up the Ghost* is not a neatly constructed memoir of a life in which, like Bauby, Mantel can document her identity pre-illness before proving she is in many ways unchanged. Rather, it is an autopathography which explores a lifelong battle between illness and identity, in the process attempting to assert for the first time an identity. Mantel’s relationship with identity is further seen in the observational narrative stance she adopts when presenting her early childhood: ‘In no. 58

Annie Connor starts a game. You go into a corner of the room. She into another. You both shout, very loud... Then you just run about the room' (30-31). This scene, and many others, read like a vignette. Rather than using past tense descriptive language, it appears Mantel is, along with the reader, watching her young self. As a result, Mantel as child and Mantel as adult become detached, and this need to assert her identity organically is further recognised. This separation is often rooted in illness. Moments of joy become torn apart by sudden bouts of illness and when she suffers she is divided: 'I am trying to die and I am trying to live... I feel myself taken by the current, tugged away.' (53) There is a forceful separation always evidenced in Mantel's life, with her identity never being created independently by herself as a child, but rather being torn apart by illness or gender roles. Of illness, Jurecic remarks that illness experience 'can break a life in two' (Jurecic 2012: 10) For Mantel, this two is not pre- and post-illness, but rather two disconnected parts of one whole self *throughout* illness: the person she is and the person she longs to be. By writing down the convoluted memories of her childhood though, Mantel processes her past, defining the ghosts that have accompanied her and differentiating the self she was from the self she wants to be. For Mantel, writing serves as the tool to which her identity can be discovered Within the text, writing is always placed in close proximity to her illness: 'They were the years in which perhaps half a million words were drafted and redrafted... ten thousand painkillers were downed by me' (Mantel 2013: 3). She writes secretly as a child on a magic slate, journals when in hospital, as a distraction when researching projects, and every morning 'to write myself into being.' (225). Writing is what allows Mantel to retaliate against the lifelong opinion of her as weak, sickly, overambitious or mentally ill. It both forms and represents Mantel's identity, and autopathography is what pushes this asserted identity forward in to the public eye, as if a final act of proving who she truly is. As Kusek argues, it is writing is Mantel's 'singular method of coming to terms with [losses]' (Kusek 2014: 187). I would extend this analysis to say that writing is Mantel's singular method of coming to terms with not just the losses of her life, but of every aspect of her life; in short, her identity. As Kusek furthers, '*Giving Up the Ghost* appears to me to be the "truest" form of autopathography as it does not only provide a chronicle of survival, but, in its very essence, is the means of survival.' (188) Mantel's autopathography is not only an illness narrative which deals with self pre- and post-illness, but is an illness narrative which negotiates a life dictated by illness. In successfully self-diagnosing her illness, Mantel disproves the gendered biases of her childhood, escaping the misdiagnoses of overambition and female stress. She outgrows and proves wrong outdated social and medical attitudes, and in producing her autopathography, uses her platform to

assert this. The book's concluding line – 'This is your daughter Hilary speaking, and this is her book.' (Mantel 2013: 252) – serves as the final assertion of Mantel's identity. No longer does she have to escape her childhood self – 'Hilary' - but rather she can accept it as a part of her, as equally important in the formation of her identity as *Giving Up the Ghost* – 'her book' - itself.

Autopathography affords the author space in which they can represent their illness. Be it a lifelong illness or sudden disability, by writing their experience, there is a freedom that transcends the clinical, depersonalized attitudes often associated with medical writings. Jean-Dominique Bauby's *The Diving-Bell and the Butterfly* and Hilary Mantel's *Giving Up the Ghost* see their authors explore and negotiate their identity. Bauby's autopathography affords him the opportunity to *reassert* his identity amidst dominant medical attitudes and social perceptions of disability. He frees himself from the diving-bell of his body, not only reasserting his pre-stroke identity, but also coming to terms with a transformative sense of self, in which he gains clarity and reinforcement of the things which ultimately define him. Mantel's experience differs in that she negotiates a lifelong illness, misdiagnosed and mistreated, and contrary to Bauby, she is asserting for the first time her identity not only to those around her but to herself. By reminiscing, reimagining and reflecting on her past, Mantel escapes the restraints of gendered medical diagnosis and a gender prejudiced childhood. While they are to different degrees asserting and reasserting their identity, Bauby and Mantel both negotiate a sense of self throughout their autopathographies, and as Hawkins argues, these 'life-writings give voice to the voiceless and insist that the voice be heeded' (Hawkins 1999: 167). Be that literal or metaphorical voiceless-ness, both Mantel and Bauby move beyond the restricted self through their writing, ultimately discovering and presenting their truest identity within their texts.

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