“De simple malade j’étais devenu un handicapé”: interrogating the construction of ‘disability’ in Jean-Dominique Bauby’s *Le Scaphandre et le papillon*

**Introduction**

On December 8th 1995, at the age of 44, French journalist Jean-Dominique Bauby had a massive stroke which put him into a coma of several weeks. He regained consciousness at the end of January 1996 in a bed in a hospital in Berck-sur-Mer and in the summer of that same year he wrote a powerful autopathographical memoir. The resulting text, *Le Scaphandre et le papillon*, uses a patchwork of 29 vignettes which combine reflections on his current situation and memories from his “première vie” to create an evocative and moving depiction of Bauby’s shift in subject-position from ‘non-disabled’ to ‘disabled’.[[1]](#endnote-1) This article builds on work being done in the emerging discipline of Critical Disability Studies firstly to investigate how Bauby’s text subtly challenges outdated notions of disability, and secondly to offer an innovative way of reading first-person accounts of disabled selfhood which celebrates the creative and intellectual potential of disability.

In her critical-disability-studies-inflected reading of Guy de Maupassant’s short story ‘L’Aveugle’, Catherine J. Kudlick offers a description of the outmoded, medical model of disability which most Angl0-American disability studies scholars and activists now reject:

This older view regards disability as a problem or lack located in the individual. It sees disability only as an isolated person’s physiological defect or social deficiency. Dating from the nineteenth century, it prescribes medical intervention and rehabilitation as the only effective remedies. It celebrates individuals who engage in heroic striving to overcome personal tragedy. For those who are not heroes, it offers pity and charity.’[[2]](#endnote-2)

Throughout her useful analysis of paralysis in two contemporary French novels, Sam Haigh persuasively shows that whilst this medicalized view of disability is becoming less widely-held in Britain and the States, it still persists in France.[[3]](#endnote-3) It is therefore fair to assume that before his accident, Bauby, like most people without personal experience of disability, would have espoused this still commonly-held view which insists that disability is a tragic, life-limiting condition which reduces a person’s chances of fulfilment or happiness and demotes them from an individual to a mere patient. Indeed, as Jewell convincingly shows in her subtle and complex analysis, this view was probably also held by Julien Schnabel, whose 2007 filmic adaptation of the memoir “retains both the tragic and the metaphorical connotations [of disability] found so problematic in critical disability studies”.[[4]](#endnote-4) In the penultimate chapter of his extraordinary memoir Bauby paints a picture of his “derniers moments de Terrien” (Bauby 125) which evokes the glamorous and exciting life he led as editor-in-chief of *Elle* magazine, husband, lover, father, theatre-goer, aficionado of high-end cars and connoisseur of luxurious seafood. Bauby’s clear appreciation of the finer things in life, as well as his editorship of a leading women’s magazine, suggests not only that he held conventional views on the desirability of beauty and health - and the consequent undesirability of disability - but also that he played a key role in reinforcing such views through both his journalism and his lifestyle. Indeed, Bauby’s pre-stroke attitude to disability is revealed in the book’s first chapter, “Le Fauteuil”. Shortly after his return to consciousness, Bauby is visited by the entire medical team who come to watch the physiotherapist assess his suitability for a wheelchair. As he describes this moment, which marks the beginning of his shift in subject-position, he says, “De simple malade j’étais devenu un handicapé” (Bauby 14). This apparently straightforward phrase is in fact crucial because it betrays his negative feelings towards disabled people. By saying “un handicapé” rather than “une personne handicapée” or “une personne en situation de handicap”, Bauby is demonstrating a probably unwittingly ableist approach to disability which is typical of his milieu, generation and social standing. This nominalization of disability, whereby one aspect of a person becomes their only characteristic by its shift from adjective to noun is, as David Bolt shows in his reading of Gide’s *La* *Symphonie pastorale*, an effective means both of depersonalization and of infantilization.[[5]](#endnote-5) Like most non-disabled people, Bauby’s language reveals that he sees disabled people as somehow less than human, stripped of their personhood, hidden behind their disability which becomes their one defining trait. By describing a disabled person in these terms, he denies the disabled person’s autonomy and sees them as an object without value, or, at least, without the same value as his non-disabled self.

Bauby’s turn of phrase is of course all the more remarkable because it is his own newly disabled self which he is describing using this depersonalized nominal construction. Whilst the kind of non-disabled person Bauby was before his stroke is used to thinking about the disabled other in these terms, the fact that it is Bauby’s post-stroke voice which describes his new self in this way merges his pre-accident perspective with his new disabled status so that we understand both how it feels to contemplate the disabled other, and, simultaneously, how it feels to be a disabled person judged by a non-disabled gaze. Bauby’s shocked reaction to his discovery that he is not about to recover from what he had assumed was a temporary ailment, is the catalyst for this shift in subject position which will in turn become the subject of his autopathography. When disability occurs suddenly, as is the case for Bauby, there is an unexpected jolt in subject position: by transitioning from the subject-position of ‘non-disabled’ to that of ‘disabled’, the self temporarily becomes other until the new subject-position can be assimilated. Other changes in the hierarchical binary oppositions which still structure Western society – from white to black, from male to female, from straight to gay – do not usually happen quite so unexpectedly, so immediately and without the prior knowledge or consent of the person concerned.[[6]](#endnote-6) Bauby quickly begins to appreciate his new status. After the initial shock of his situation, which he describes as “Aussi aveuglante qu’un champignon atomique. Mieux acérée que le couperet d’un guillotine” (Bauby 15), he presents his refusal to wear the recommended tracksuit, and the joy with which he is reunited with his “hardes d’étudiant attardé” as “un symbole de la vie qui continue. Et la preuve que je veux être encore moi-même” (Bauby 23). This reference to his selfhood is the first indication that as *Le Scaphandre et le papillon* develops, Bauby not only embraces but also asserts his new disabled subject position. His witty, self-mocking and often ironic prose demonstrates that he does not see his paralysis as tragic. He has moments of sadness, of course, but he is neither overwhelmed by grief nor rendered passive by debilitating self-pity. Whilst there may be sound neurological reasons for Bauby’s upbeat attitude, it is also clear, as he points out, that it is only once he is paralysed that he is able to appreciate the advantages of this particular way of being.[[7]](#endnote-7) Indeed In what follows we will see that Bauby is able to use his narrative to celebrate his new disabled self precisely because of the apparently paradoxical intellectual and creative freedom it allows him.

**Autopathography and the Medical Model**

Autopathographies are a form of life-writing in which the ill or disabled person is able to tell their own story, rather than letting it be told by doctors or caregivers. As G. Thomas Couser points out, these narratives proliferated towards the end of the twentieth century to the extent that “disabled people have initiated and controlled their own narratives in unprecedented ways and to an extraordinary degree.”[[8]](#endnote-8) Their interest in the disabled subject’s own experiences suggests that autopathographies tend to work against the medical model’s privileging of the notion of the cure by calling into question the authoritative and frequently dehumanizing processes upon which the modern bio-medical sciences depend. As a means by which disabled people can reclaim the agency denied to them by an impersonal medical system, autopathographies are thus always in a spoken or unspoken dialogue with the medical establishment and therefore also with the medical model of disability, even if these are not always the same thing, and even whilst such texts are endeavouring to assert their independence from this dehumanizing model.

Like many autopathographers, Bauby is scathing in his critique of the often arrogant and out-dated doctor-centric approach which he experiences during his first months in Berck. His harsh account of the brusque ophthalmologist who comes to sew up his right eyelid without either introducing himself or explaining the procedure, exemplifies the kind of overly medicalized approach which this figure comes to represent for Bauby:

Mais le bonhonne, s’il passait ses journées à scruter la prunelle d’autrui, ne savait pas pour autant lire dans les regards. C’était le prototype du docteur Je-m’en-fous, hautain, cassant, plein de morgue, qui pour sa consultation convoquait impérativement les patients à huit heures, arrivait à neuf, et repartait à neuf heures cinq après avoir consacré à chacun quarante-cinq seconds de son précieux temps. (Bauby 59-60)

Bauby is so shocked by the ophthalmologist’s dismissive attitude that after a few weeks he begins to wonder if the hospital has not in fact decided to employ him precisely because of his rebarbative nature, “pour catalyser la sourde méfiance que le corps médical finit par faire naître chez les patients de longue durée” (Bauby 60). It is as if this particular doctor’s role is not only to treat Bauby’s eyes, but also, and perhaps more importantly, to remind him, and us, of the problems associated with the medical model of disability.

The ophthalmologist is an extreme example of the medical establishment’s paradoxical inability to communicate with its clients, but he is not the only medic in Berck who fails to establish a meaningful relationship with Bauby. After some weeks at Berck, Bauby comes to the unfortunate conclusion that not many of his carers have any real desire to communicate with him. Only his speech therapist Sandrine and a psychologist use his bespoke communication system. The rest either do their best to interpret his facial gestures without asking him about them directly, or, worse still, abandon him whilst pretending not to notice his “signaux de détresse” (Bauby 46). It is one of the key ironies of *Le Scaphandre et le papillon* that Bauby is able to communicate better with the reader than the vast majority of his carers can communicate with him. Bauby’s unflattering depiction of the medical professionals he encounters does not mean that he is critical of medical intervention as such or of the care given to him in particular. He is well aware that he would not be alive without the hospital’s sophisticated reanimation techniques and he is extraordinarily complimentary about some of the people who work with him, particularly his “ange gardien”, the speech therapist Sandrine who not only devised his blink-speech system but is also helping him relearn to talk. (Bauby 45) But this sketch of the ophthalmologist nonetheless reveals that critics of the medical model of disability are right to highlight the dangers of a way of thinking about disability which neglects to treat its patients as autonomous and important individuals.

**Language and the Construction of Disability**

By rejecting the medical model of disability, Critical Disability scholars such as Kudlick, Haigh and Jewell urge us to view ‘disability’ as a culturally constructed concept - like gender, race, social class or sexuality - which has historically been given negative connotations by ‘normal’ society. As Lennard Davis puts it: “the ‘problem’ is not the person with disabilities; the ‘problem’ is the way that normalcy is constructed to create the ‘problem’ of the disabled person.”[[9]](#endnote-9) Davis’s position, like that of many Critical Disability scholars, is informed, at least in part, by the so-called social model of disability. This model, which originated in Britain in the 1970s as a reaction to the medical model, argues that individuals are disabled less by their own impairments than by the barriers – both physical and metaphorical – which non-disabled society places in their way. Although this model has been criticized for its refusal to take into account the individual’s lived experience of disability as well as for its reluctance to accept that impairments can impose limitations on disabled people which are distinct from the limitations imposed by non-disabled society, the emphasis it places on critical thinking, shifting perspectives and the role language can play in the valorization (or denigration) of disability makes it a fruitful theoretical framework to apply to representations of disability in literature.[[10]](#endnote-10)

The social model’s emphasis on the role of language finds a playful echo in Bauby’s personification of the letters of his specially conceived alphabet: “Main dans la main, elles traversent la chambre, tournent autour du lit, longent la fenêtre, serpentent sur le mur, vont jusqu’à la porte, et repartent pour un tour” (Bauby 25). His description of the letters’ nocturnal antics can be read as both a reminder of language’s slippery ability to exceed the meanings we try and assign to it, its tendency to say more (or less) than we want it to, and a joyful celebration of the ability to communicate with the outside world which this new version of the letters represents for Bauby.

The emphasis which Bauby’s celebration of his new alphabet places on the material conditions of the book’s production reveals the primordial importance of language to and in his project. The meticulous, time-consuming and painstaking nature of the book’s composition foregrounds Bauby’s linguistic choices and invites the reader to accord significance to each word he or she reads. Because the text is written letter by letter, Bauby has time to choose each word carefully for the precise effect it creates. This method both emphasizes the work of communication – in contrast with the ease with which Bauby the editor-in-chef manipulated language – and also explains the extraordinary combination of poetry and lucidity which characterizes the memoir. For Bauby, the writing of the book is a two-stage process which depends on both his own, and others’ affinity with the French language. During the first, solitary, phase, he composes, perfects and then memorizes his text. As he explains in the Prologue: “Dans ma tête je malaxe dix fois chaque phrase, retranche un mot, ajoute un adjectif et apprends mon texte par cœur, un paragraphe après l’autre” (Bauby 11). Unlike those writers who can write or type their own manuscripts, Bauby has to prepare everything in advance before ‘dictating’ it to his interlocutor. The quotation marks around ‘dictate’ highlight the fact that this process is not the conventional kind of dictation in which the active and creative writer transmits his or her text to a passive (either human or machine) recipient. Bauby’s writing is much more participatory because it requires the active input of his interlocutor. Bauby describes this practice of dual-dictation thus:

On m’égrène l’alphabet version ESA jusqu’à ce que d’un clin d’œil j’arrête mon interlocuteur sur la lettre qu’il doit prendre en note. On recommence la même manœuvre pour les lettres suivantes et s’il n’y a pas d’erreur, on obtient assez vite un mot complet, puis des segments de phrases à peu près intelligibles. Ça c’est la théorie, le mode d’emploi, la notice explicative. Et puis il y a la réalité. (Bauby 26)

Bauby’s insistence here on the difference between theory and practice emphasizes the subjective nature of this kind of communication, which depends not only on his own memory and preparatory work but also on the active participation of his transcriber. Whilst the book’s co-creator, Claude Mendibil, is rather good at transforming Bauby’s blinks into text, the same cannot be said for his other interlocutors. Some people are much better at this kind of exercise than others. Given that he knows his work will be read by all those friends and colleagues who communicate with him using the ‘ESA’ method, Bauby playfully describes their varying abilities to successfully finish the words he starts. In a move which can be read as a ludic echo of the depersonalizing categorization with which society tends to compartmentalize disabled people, Bauby characterizes his acquaintances according to their relationship to his words. Whilst ‘cruciverbistes et scrabbleurs ont une longueur d’avance’ and ‘les filles se débrouillent mieux que les garçons’, ‘les émotifs’, ‘les évasifs’, ‘les besogneux’ and ‘les impulsifs’ find it much more difficult to get used to the ‘code’, “comme on nomme aussi ce mode de traduction de […] pensées” (Bauby 26-27). As a writer, journalist and lover of the elegance of the French language, Bauby in fact enjoys the unpredictable, surreal or fanciful turn which his conversations can take. As he points out: “J’ai cependant compris la poésie de ces jeux de l’esprit le jour ou, comme j’entreprenais de réclamer mes lunettes, on m’a élégamment demandé ce que je voulais faire avec la lune“ (Bauby 28). The reference to “jeux” as well as to crossword puzzles and scrabble, and the joyful tone of his words, emphasizes the pleasure he takes from the imaginative potential of his situation.

The importance which Bauby affords to word-play within the text, as well as his love of richly illustrative language, demonstrated, for example, in the text’s title, invites us to read his description of his writing method, and the difficulties which some of his friends experience with it, as a metaphoric evocation of the position of a disabled person living in a non-disabled society. Even though most people have enough common sense to instinctively know how to behave in a courteous and respectful way towards a fellow human being, the reality of an interaction with a disabled person is difficult for most people to deal with.[[11]](#endnote-11).

The hospital’s other patients, whom Bauby baptises “tourists” (Bauby 37) because of their transitory presence in the hospital, as opposed to his more long-term residence, find his inability to talk to them disturbing. Whilst they are more than happy to talk amongst themselves, they are unable to meet his eye when they encounter him: “J’aimerais avoir ma part dans toute cette gaieté, mais, dès que je pose mon œil unique sur eux, jeune homme, mamie, clochard, détournent tous la tête et éprouvent un besoin urgent de contempler le détecteur d’incendie fixée au plafond. Les ‘touristes’ doivent avoir très peur du feu” (Bauby 39).

The tourists’ reluctance to make eye-contact with Bauby finds an echo in a visit to Lourdes which he undertook some years previously. This time it is Bauby who is the gawking tourist casting furtive glances at the hordes of ill and infirm pilgrims: “A la dérobée j’observais les malades, ces mains tordues, ces visages fermés, ces petits paquets de vie tassés sur eux-mêmes” (Bauby 69). But unlike his fellow inmates now at Berck, Bauby’s pre-stroke tourist self was not afraid to interact with these patients: “L’un d’eux croisa mon regard et j’esquissai un sourire mais il me répondit en tirant la langue et je me sentis bêtement rougir jusqu’aux oreilles comme pris en faute” (Bauby 69). Bauby’s mortified reaction to the anonymous pilgrim’s unexpected gesture exemplifies non-disabled society’s tendency to assume that illness or disability transforms people into passive recipients of our good wishes. The eruption of this troublesome tongue into Bauby’s visit, and thus into his narrative, indicates the disabled person’s desire to undermine the expectations of the non-disabled starer. As such this apparently minor incident can in fact be read as a mise-en-abyme of *Le Scaphandre et le papillon,* for in it we find the same desire to undermine the expectations of non-disabled people by asking them to think again about what they think they know about disability. If Bauby could stick out his tongue he would. Instead he imagines equally impertinent responses to the medics’ questions, such as this delightful fantasy exchange with the ophthalmologist: “A son éternelle question, ‘Voyez-vous double?’, je n’aurai plus le plaisir solitaire et innocent de m’entendre lui répondre en mon for intérieur, ‘Oui, je vois deux cons au lieu d’un’” (Bauby 60).

The irreverent humour of this imaginary exchange notwithstanding, Bauby’s interior monologue clearly shows that at least some of the difficulties and frustrations of his present situation are caused not, or not only, by his own physical state, but also, and perhaps even more so, by the inability of those around him to relate to him in meaningful and sensitive ways. Overboe’s criticism of those readers who “usually privilege an able-bodied perspective” could just as easily refer to several characters within the narrative. As Overboe goes on to say: “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.”[[12]](#endnote-12) The unnamed porter exemplifies this failure to treat Bauby as an individual. Every day he takes Bauby back to his room after his daily physiotherapy session, and every day he wishes him a well-meaning but thoughtless “‘bon appetit’ à la jovialité calculée” (Bauby 41) which sits more than a little uneasily with the fact that Bauby is fed by “une sonde reliée à l’estomac” (Bauby 41). Whilst it is shocking in our era of political correctness that a medical professional working with profoundly disabled people should not have been trained to avoid this kind of inappropriate language, it is unfortunately not all that surprising. More serious, however, is the waspish gossip of Bauby’s Parisian acquaintances which is immensely hurtful to him not only because of their assumptions that his paralysis has robbed him of his selfhood, but also because of the way it is gleefully proffered with “la gourmandise de vautours qui ont découvert une gazelle éventrée” (Bauby 88) and with no attempt to distinguish fiction from reality. Once Bauby’s friends have made him aware of the erroneous assertions of the Parisan rumour-mill, he decides to engage in the intellectual equivalent of the Lourdian tongue incident, that is, he decides to write a circular letter which he sends to around sixty friends and acquaintances. Like the wagging tongue, the letters Bauby writes and receives as a result of the Parisian gossips can be read as a mise-en-abyme of the text which refers to them. These letters are a striking example of the crucial role which language plays in Bauby’s struggle firstly to construct a disabled subject-position and, secondly, to convince others to value this subject-position as they would a non-disabled one. As soon as Bauby starts receiving letters in response to his first group missive, he is witness to “un curieux phénomène de renversement des apparences” (Bauby 89) whereby it is those people with whom he has the most superficial relations who are precisely those most likely to evoke serious subjects in their answers. As well as reminding us not to judge by appearances, these letters thus demonstrate that the language we use can both indicate and influence our own and others’ attitude to disability. As Bauby points out with his characteristic use of metaphor: “tout le monde a compris qu’on pourrait me joindre dans ma scaphandre, même s’il m’entraine parfois aux confins de terres inexplorées” (Bauby 88).

**Doubling and Multifaceted Identity**

The gap between Bauby’s paralysed body and the incredible suppleness of his mind which his round-robin letter reveals is further expressed by the book’s title image. Bauby’s body has become a heavy and restrictive diving-bell which surrounds and imprisons him as it drags him down to the murky depths of an unknown and unknowable ocean of despair. His mind, on the other hand, is as light and as free as a butterfly. But this does not mean that his mind is enacting a straightforward escape from his now redundant body. Rather, it is precisely the ever-present physicality of this body which Bauby seeks to capture in his prose. His relationship with his body both generates, and becomes the subject of his narrative. Bauby is no longer the kind of worldly-wise earth-dweller he describes in his penultimate chapter. He is either below ground or above it; sometimes he is sinking, sometimes he is flying but he is always responding to the complicated relationship between mind and body whilst simultaneously trying to express it. This double identity, in which his body and his mind have become dislocated from one another, is effectively illustrated in his description of his own reflection. Whilst he is looking at a glass case which contains a picture of Empress Eugénie, the wife of Napoléon III, and one of the hospital’s original patrons, Bauby notices that:

Une figure inconnue est venue s’interposer entre elle et moi. Dans un reflet de la vitrine est apparu le visage d’un homme qui semblait avoir séjourné dans un tonneau de dioxine. La bouche était tordue, le nez accidenté, les cheveux en bataille, le regard plein d’effroi. Un œil était cousu et l’autre s’écarquillait comme l’œil de Caïn. Pendant une minute j’ai fixé cette pupille dilatée sans comprendre que c’était tout simplement moi. (Bauby 31)

Valerie Raoul’s assertion that this description is “a graphic portrayal of the split subject ensuing from Lacan’s mirror stage” demonstrates, like the title image, that the relationship between body – that is, how Bauby appears from the outside – and mind – how he sees himself from within – is indeed a complicated one.[[13]](#endnote-13) Unlike *Elle* magazine, which insists on the importance of physical appearance, beauty, and health, Bauby is here separating himself from the corporeal constraints with which “les Terriens” are generally obsessed. The moment it took him to recognize his own physical appearance, represents the gap which now exists between how he looks and how he feels. When he was editor of *Elle* magazine, his outward appearance was an unproblematic reflection of his inner self. But since his stroke, his bodily identity no longer fits with his mind’s view of himself. And yet it is this bodily identity which most people assume to be a true reflection of him. Whilst acknowledging the horror of his own physical appearance, Bauby simultaneously demonstrates that he is increasingly distant from his physical self. This acknowledgement that his identity now encompasses multiple elements which do not necessarily coincide is further explored through his frequent intertextual references to film and literature. One such example is Bauby’s identification with the character of Noirtier de Villefort, “figure assez sinistre du *Comte de Monte Christo*”, whom he describes as “le premier ‘Locked-In syndrome’, et à ce jour le seul, apparu en littérature” (Bauby 53). Like Bauby, Noirtier is completely paralysed and can only communicate by blinking. Bauby’s evocation of “cet handicapé profond” not only reminds us of his love of literature, but also validates his situation, and his legitimacy as a narrator, by positioning *Le Scaphandre et le papillon* in relation to Dumas’s nineteenth-century classic. Bauby explains that he re-read *Le Comte de Monte-Christo* just before his accident and, what is more, he had “le projet, sans doute iconoclaste, d’écrire une transposition moderne du roman” (Bauby 54) Although Bauby claims that he has not had time to “commettre ce crime de lèse-majesté”, his reflexive reference to Dumas’s classic, along with the reference he makes to a play he would like to write based on his current situation, in fact invites us to read *Le Scaphandre et le papillon* as an intertextual response (although not the response he originally intended) to Dumas *père*’s novel. In Bauby’s version, Dumas’s third-person narrator is rejected in favour of a first-person narration by the paralysed Noirtier, a sleight of hand enabled by Sandrine’s innovative dictation method.

As well as increasing our ability to empathize with his situation, and validating his work as part of the French literary canon, Bauby’s identification with a range of solitary or trapped figures also emphasizes the universality of his condition. Without denying the specificity of his Locked-In Syndrome, a denial which would undermine Critical Disability Studies’ insistence on the centrality of embodiment, such comparisons nonetheless encourage us to read his situation as a metaphor for human solitude more generally.[[14]](#endnote-14) The comparison Bauby establishes between himself and his aging father exemplifies this desire to dedramatize his own situation: “Nous sommes tous les deux des ‘Locked-In Syndrome, chacun à sa manière. Moi dans ma carcasse, lui dans son troisième étage” (Bauby 50). By demonstrating the similarity between his own situation and that of his father, Bauby downplays the horror of LIS by suggesting that despite his total paralysis, he is in fact no more or less trapped than a house-bound pensioner. Indeed, this comparison suggests that most of us are ‘locked-in’ in some way: Bauby’s situation is the most extreme example of a relatively common facet of the human condition.

If Bauby uses such comparisons to demystify his paralysed status, and thus suggest that disability is not as much of a difference from ‘normality’ as ableist society would have us believe, his text also insists, like the social model, on the plural, changeable and constructed nature of identity. Throughout the text, Bauby confounds the reader’s belief in a stable self by also identifying with a range of characters who seem, at first, at odds with his current situation. But these figures, who again are mostly taken from film or literature, in fact demonstrate his increasing separation from the reality of his “première vie” and his subsequent construction of a liberating fantasy world where he is no longer constrained either by his own corporeality or by society’s expectations of it. Inspired by his school friend Olivier, who would spend his days inventing tall tales about himself and his family, Bauby creates a plethora of fictional identities for himself. By constructing a “géographie imaginaire de l’hôpital” (Bauby 34-35), he uses his imagination to assert control over his situation, rejecting the hospital’s rules and timetables in favour of a more creative reality. Thus, the south-facing sun terraces of the Pavillon Sorel become “Cinecitta”, an ever-changing film set which allows Bauby to transform himself into “le plus grand réalisateur de tous les temps” (Bauby 35). Bauby’s celebration of his creative imagination, and his ability to cast himself in a variety of roles, from ‘Pierrot le Fou’ to a Grand Prix racing driver, serve to remind those people, such as the Paris gossips, who tend to associate paralysis with passivity, that the mind can be as imaginative and as creative as the body is inert.

**The Language of Sensuality**

Thus far we have seen how Bauby’s use of language to create not only his text but also his disabled self, emphasizes both the culturally constructed nature of disability - and the subsequent need to constantly challenge erroneous conceptions of it - and the ever-changing nature of identity. We have already seen that Bauby’s text is written in a rich and evocative prose and his poetic use of imagery also demonstrates the extent to which he can appreciate the sensuality of the physical world through his creative reconstructions of it. Language becomes not only a tool of communication but also a means of expressing the immediacy of physical sensations. As James Overboe explains, “Bauby’s recognition of his continuing sensuous and embodied life creates the possibility of a space for the memory of the sensuality of experiencing food”.[[15]](#endnote-15) The text thus poses important philosophical questions relating to the extent to which language can be said to create or reflect physical sensations. Rather than letting the porter’s insensitive ”bon appétit” reaffirm his lack of connection with the physical world, Bauby sees it as an invitation to an imaginary feast: “pour le plaisir, j’ai recours à la mémoire vive des goûts et des odeurs, un inépuisable réservoir de sensations.” (Bauby 42) Indeed, unlike the complicated and often ultimately disappointing reality of restaurant bookings, shopping lists and indigestion, Bauby’s “garde-manger imaginaire” is always full of perfectly cooked dishes. It is notable that whilst at the beginning of his “long jeûne” Bauby has a bulimic’s obsession with food; as the months pass, and he becomes more settled in his imaginary world, he is less inclined to spend hours concocting his favourite dishes. This is not to say that Bauby can do without sensorial stimulation. The odour of chips being cooked by the beach is one of his favourite smells. But as his fantasy world begins to take precedence over his corporeality, he has less need to remind himself of the “première vie” he has left behind him.

Bauby’s most remarkable images are ones which evoke the sensations of bodily pleasure which are no longer available to him. The apparently flippant comment “je m’imagine bien lécher une boule de vanille sur un jeune épiderme rougi par le soleil” (Bauby 92) is a case in point. In this simple sentence, Bauby uses the contrast between food and flesh, between cold ice-cream and warm skin, to create a frisson of erotic excitement which reminds us that his mind is still more than capable of remembering the physical pleasures which his body can no longer experience directly. Indeed, Bauby’s descriptions of sexual pleasure are particularly revealing for their ability to invite the reader to rethink his or her preconceived notions of disability. Whilst his description of the daily sponge bath administered by the nurse, evokes the disability-as-infantilization association triggered by his earlier nominalization, his explanation of how he sometimes “trouve cocasse d’être, à quarante-quatre ans, nettoyé, retourné, torché et langé comme un nourrison” (Bauby 22) simultaneously evokes the vague pleasure which such interactions occasion. His half-mocking, half-aroused tone encourages us to reconsider our perhaps erroneous ideas concerning the limited or non-existent sexuality of people with Locked-In Syndrome. Similarly, in “Les Demoiselles de Hong-Kong”, Bauby discusses the bar Félix in the Peninsula Hotel in which a French designer has created bar stools featuring the photographs of key Parisian figures, including Bauby himself. As he imagines his colleagues visiting this bar during their annual congress, Bauby hopes that no one will tell the barman about his stroke because: “Ces gens-là sont tous superstitieux et il n’y aurait plus aucune de ces ravissantes petites Chinoises en minijupe pour venir s’asseoir sur moi” (Bauby 111-112). The coarse and somewhat bawdy tone of this double-entendre feels shocking because this rather vulgar evocation of sexual desire is not usually found in this kind of text. The fact that it is Bauby’s mind rather than his body which is able to evoke this desire also reminds us that despite what *Elle* magazine’s editors might want us to believe, erotic desire is not necessarily or not only related to, or dependant on the body’s ability to respond physically to sexual stimulation.

**Conclusion: Disability Gain**

As well as highlighting the constructed nature of ‘disability’, which is always positioned in relation to the ‘normal’ or what I prefer to call the ‘non-disabled’ world, critical disability studies also aims to celebrate disability for its own sake, as a different, but equally valid, way of being in the world rather than as a tragedy deserving of pity. This notion of ‘disability gain’ which is borrowed from the theory of ‘deaf gain’, - a school of thought which, like *Le Scaphandre et le papillon,* explores the positive possibilities of linguistic plurality - is also manifested in Bauby’s text, notably through his celebration of interdependency and his insistence on the creative and artistic potential of Locked-In Syndrome.[[16]](#endnote-16) My reading of *Le Scaphandre et le papillon* invites us to re-examine several deeply-held misconceptions not only about disability, and the value of disabled subjectivity, but also about modern society in general. The privileged role accorded to Bauby’s mind throughout the text encourages us to rethink the value which we, like *Elle* magazine,usually place on physical appearance. The collaborative way in which the text is produced calls into question the assumptions we tend to make about the importance of autonomy and independence. In a move which foreshadows the challenge which several Disability Studies scholars, including Lennard Davis, Tom Shakespeare and David Bolt, have made to the independence / dependence hierarchical binary opposition, Bauby’s text reveals that asking others for help is not a sign of weakness but a means of creating a powerful and captivating memoir.[[17]](#endnote-17)

1. Jean-Dominique Bauby, *Le Scaphandre et le Papillon* (Paris: Robert Laffont, 1997) [↑](#endnote-ref-1)
2. Catherine J. Kudlick, ‘Guy de Maupassant, Louisa May Alcott and Youth at Risk: Lessons from the New Paradigm of Disability’, *Paedagogica Historica*  45.1–2 (February–April 2009): 37 [↑](#endnote-ref-2)
3. Samantha Haigh, ‘Personal or Political? Representations of Disability in Contemporary French Fiction’, *Journal of Literary & Cultural Disability Studies* 6. 3 (2012): 307-325. [↑](#endnote-ref-3)
4. Tess Jewell, ‘Blinding the Screen: Visualizing Disability in *Le Scaphandre et le papillon*’, *Mosaic: a journal for the interdisciplinary study of literature* 46.3 (2013):110. [↑](#endnote-ref-4)
5. David Bolt*, The Metanarrative of Blindness* (Ann Arbor, U of Michigan P, 2014), 38-39 [↑](#endnote-ref-5)
6. The case of Herculine Barbin, famously discussed by Michel Foucault, reminds us that shifts in gender identity can occasionally occur in a similarly unexpected way. See Michel Foucault, *Herculine Barbin, dite Alexina B.* (Paris: Gallimard, 1978) [↑](#endnote-ref-6)
7. Simon Kemp has argued that Bauby’s astonishing lack of despair finds an explanation in some recent neurological findings which were foreshadowed by the theories of Henri Bergon. See Simon Kemp, ‘Bergson, Bauby and the Neuroscience of Emotion’, *French Studies Bulletin* 31 (2011): 73-76 [↑](#endnote-ref-7)
8. G. Thomas Couser, ‘’Disability, Life Narrative, and Representation’ in *The* *Disability Studies Reader* (4th edition) ed by Lennard J. Davis (London and New York: Routledge, 2013), 447 [↑](#endnote-ref-8)
9. Lennard J. Davis, ‘Introduction: Normality, Power and Culture’ in *The Disability Studies Reader*, 1 [↑](#endnote-ref-9)
10. On the history, definition, merits and shortcomings of the social model see Tom Shakespeare, ‘The Social Model of Disability’ in *The Disability Studies Reader*, 207-215 [↑](#endnote-ref-10)
11. On the able-bodied person’s inability to respond to visible disability in others see Rosemarie Garland-Thomson, *Staring: How We Look* (Oxford and New York: Oxford UP, 2009), 19-20. [↑](#endnote-ref-11)
12. Valerie Raoul et al., ‘Narrating the Unspeakable: Interdisciplinary Readings of Jean-Dominique Bauby’s *The Diving Bell and the Butterfly*’, *Literature and Medicine* 20.2 (2001): 193. [↑](#endnote-ref-12)
13. Raoul et al: 187 [↑](#endnote-ref-13)
14. On the problems posed by disability-as-metaphor, see David T. Mitchell and Sharon L. Snyder, ‘Introduction: Disability Studies and the Double-Bind of Representation’ in David T. Mitchell and Sharon L. Snyder (eds), *The Body and Physical Difference*: *Discourses of Disability* (Ann Arbor: The U of Michigan P, 1997), 6 [↑](#endnote-ref-14)
15. Raoul et al: 191 [↑](#endnote-ref-15)
16. For a detailed discussion of ‘deaf gain’, see *Deaf Gain: Raising the Stakes for Human Diversity* ed by H-Dirksen L. Bauman and Joseph J. Murray (Minneapolis: U of Minnesota P, 2014) [↑](#endnote-ref-16)
17. See, for example, Bolt, 65 [↑](#endnote-ref-17)