

Benjamin Gagnon Chainey //

Hervé Guibert was a prolific French writer who died from AIDS in 1991. Jean-Dominique Bauby, editor of the magazine *Elle*, suffered a massive stroke that left him locked in his body. With the help of his speech therapist, Guibert wrote *The Diving Bell and the Butterfly* entirely by blinking one eye. When comparing photographs of both men, the similarities are striking: in the picture “Autoportrait, rue du Moulin-vert” (Guibert, 1986) and the picture of Jean-Dominique Bauby watching the lighthouse from the Hôpital maritime de Berck (Bauby, 1996), both men are lying in a bed, next to a window, seemingly (or actually) unable to move, as if the light filtering through the window was the only sensory experience they could still enjoy.

The similarity is not fortuitous, as both Guibert and Bauby raise questions about the incapacitated body’s ability to participate in activities that abled people take for granted, in particular when it comes to relationships with others. As Bauby writes of the first time he saw a lighthouse near his hospital, “I placed myself at once under the protection of this brotherly symbol, guardian not just of sailors but of the sick—those castaways on the shores of loneliness” (p. 23). Not unlike a solitary lighthouse, or perhaps a castaway, in his auto-patho-graphical documentary *La pudeur ou l’impudeur*, Guibert can be seen on the shore of the island of Elba, standing alone, naked, exposing his frail and terminally ill body to the sea.

Disability, therefore, seems to take on its full meaning: it is a reduction of the ability to act, revealing, at a time when the notion of “agency” is variously defined in academic literature, that action can never be fully divorced from the flesh-and-blood body that serves as its substrate, especially when the flesh and the blood are failing.

Guibert[i] and Bauby[ii] were both writers, and it is because of their writings that accounts of their loneliness and inability to act have reached us and that we are discussing them here and elsewhere. This fact raises the question of the role literature and the humanities (Guibert was also a photographer and filmmaker; Bauby’s story was turned into a documentary and a feature film) can play with respect to disabled and sick bodies. Mitchell and Snyder[iii] highlight that artistic endeavors attempting to represent disability have either produced “overheated symbolic imagery” or have contributed to turning disability into “a pervasive tool of artistic characterization,” in both cases failing to cater the “pragmatic needs of disabled communities and the contemporary political rights movements.” In other words, they “diagnose literature as another social requisitory of stereotypical depictions”, and to them literature and the humanities are seen mostly as using

disability to their own ends and making only futile contributions to the improvement of disabled people's lives.

However, it could be argued that Mitchell and Snyder expect from literature and the humanities what they cannot offer: they expect the arts to be "useful" in genres that are not theirs, for instance as political platforms or as faithful evidence and documentation. In doing so, they precisely divorce language from body, as if disabled bodies were different from the intellect that produces the words that describe them. What if, instead, we took seriously Susan Sontag's warning that "In a culture whose already classical dilemma is the hypertrophy of the intellect at the expense of energy and sensual capability, interpretation is the revenge of the intellect upon art." [iv] Isn't the expectation of Mitchell and Snyder, and that of other similar critics, a call to "intellectualize" the arts, but also to intellectualize the bodies in whose name they claim to speak?

What if we literature and the humanities precisely offered a way for disabled and ill bodies to participate in sociality and in the common world at their own level, as energetic and sensuous bodies? What if it precisely offered a way of resisting and countering the many intellectual projects that claim to "represent" them (in both senses of the word), such as medical-scientific and political-legal discourse, instead of letting them talk according to their own modalities? Indeed, if giving agency back to disabled and sick bodies is meant, as a humanistic project, to restore their personhood, then it should be acknowledged, following Ratcliffe, that "personal experience cannot be explained in terms of an implicit or explicit 'theory', as our sense of what persons are originates in a distinctive kind of feeling rather than a body of knowledge." [v]

An understanding of literature and the humanities as operating at a pre-interpretative or pre-theoretical level, as sensuous rather than representational, draws attention to the performative power of language. Writing is not merely representing what already took place, "It also means that we can be at the threshold of developing the terms that allow us to live." [vi] Literature, therefore, is not about *showing* that we are persons, or asking for permission to exist as persons. Literature is itself, *in or through* writing, a mode of existence, an entry into agency and personhood, a way of gaining sensuality and exploring feelings. As Bauby writes: "Speech therapy is an art that deserves to be more widely known. [...] The exhausting exercise left me feeling like a caveman discovering language for the first time" (p. 19). Through writing his novel with his speech therapist, Bauby learned again to relate to the world, to participate in a sociality from which he was suddenly shut off.

Although he did not suffer from an equally extreme withdrawal from the world, Guibert similarly felt his decaying body deprived him from fully engaging with the social world. Caught up somewhere between the certainty of death and a glimpse of faith, he gets to the point where he feels hatred towards his "fellow men" or, as he explains, "I definitely don't like them, I rather hate them instead" (p. 4). Writing *To the friend who did not save my life*, for Guibert, is not a way of explaining something, or testifying of his experience. He is quite clear on the fact that the writing process is an end in itself:

“I’m beginning a new book to have a companion, someone with whom I can talk, eat, sleep, at whose I can dream and have nightmares, the only friend whose company I can bear at present. My companion, my book, which I’d imagined would proceed according to the original flight plan, has already begun to wrestle the controls from my hands, even though I might appear to be the captain this exercise in contact flying” (p. 4).

Writing, therefore, is not about claiming, demanding, or communicating a prior state of facts, an intention, or demands. It does not need to have a further purpose, and its power lies precisely in the process rather than in the end. As Guibert writes above, there is no way of knowing where writing may take the author, as there any “flight plan” will be diverted along the way. Again, the process of writing cannot be intellectualized in a plan prior to the act of writing, in the same way as the body cannot be reduced to an intellectual project: “I was truly convinced I was lost [...] I was able to believe myself saved by the luckiest of chances [...] I have a sense of the structure of this new book I’ve been harboring within myself all these last weeks, but I don’t know how it will unfold in its entirety” (p. 2).

Bauby wrote his book by blinking an eye; Guibert followed the evolution of his decaying body in his AIDS writings. Both wrote not so much as a political activity, or to actuate change *following* their writing, but – in agreement with both Sontag and Butler – because writing itself operates (social) change: it connected them to a world in the only way they felt was possible, the only one that was in tune with their disabled body, that attached them, if not to specific people, to humanity, and that constituted them as *persons*.

[i] In particular, see Hervé Guibert. (1993, originally 1990). *To the friend who did not save my life*. London, UK: Serpent’s Tail.

[ii] Jean-Dominique Bauby. (1997). *The diving bell and the butterfly*. New York, NY: Random House.

[iii] David T. Mitchell and Sharon L. Snyder. (2013). “Representation and Its Discontents. The Uneasy Home of Disability in Literature and Film.” In *Handbook of Disability Studies*. Thousand Oaks, Calif.: Sage Publications, p. 195-196.

[iv] Susan Sontag. (1966). *Against Interpretation and other essays*. New York: Farrar, Straus & Giroux, p. 13.

[v] Matthew Ratcliffe. (2013). “The Structure of Interpersonal Experience”. In Rasmus Thybo Jensen and Dermot Moran (Eds.). *The Phenomenology of Embodied Subjectivity*. Cham: Springer International Publishing. p. 224.

[vi] Judith Butler. (2015). *Notes Toward a Performative Theory of Assembly*. Cambridge: Harvard U. Press. p. 40.

