

## Patricia Lay-Dorsey's Visual Narrative of Chaos and Quest

Published in 2013, *Falling into Place: Self-Portraits* documents Patricia Lay-Dorsey's daily journey of living with Multiple Sclerosis. Twenty years after her diagnosis, this American artist decided to take photos of herself so as to come to terms with her aging and disabled body, weaving a visual narrative that is both intimate and powerful. In this article, I look at Lay-Dorsey's visual pathography in light of Arthur W. Frank's narrative types of chaos and quest, exploring how her work combines traits of both categories as a way to eschew common (mis)representations of disabled people as "pitiable" and "inspiring." On the one hand, the narrative outlined by *Falling into Place* is chaotic, giving an account of one's lack of control in the face of a disease such as MS. Though Lay-Dorsey finds it uncomfortable to share these private moments of vulnerability, she takes her illness as a journey where chaos "falls into place," a quest that allows the photographer/subject to accept and celebrate her body and where a disabling illness is taken as a possibility of growth.

### 1. Introduction

Narrative and the (re)creation of selfhood are widely interrelated, with life being frequently understood as a story and narrative taken as constitutive of the self.<sup>1</sup> Indeed, according to Hannah Arendt, what defines human life as such is precisely its narrativity: "The chief characteristic of this specifically human life, whose appearance and disappearance constitute worldly events, is that it is itself always full of events which ultimately can be told as a story" (1958, 97). In the context of illness and healthcare, narrative becomes a particularly relevant way to (re)create meaning, as Rita Charon points out in *Narrative Medicine: Honoring the Stories of Illness*: "As an instrument for self-knowledge and communion, narrative is an irreplaceable – and often silent or at least transparent – partner to human beings as they make and mark meaning, coping with the contingencies of moral and mortal life" (2006, 40). "Narrative Medicine," as coined by Charon, is concerned with the appreciation of words and language as a unique way of accessing the different dimensions of illness, that is, "medicine practiced with these skills of recognizing, absorbing, interpreting, and being moved by the stories of illness" (ibid., 4).<sup>2</sup>

A self-described "artist-turned-photographer" (Lay-Dorsey 2013, 103), Patricia Lay-Dorsey was diagnosed in 1988 with Primary Progressive Multiple Sclerosis, a chronic and degenerative disease that is characterized by worsening neurological function and increasing disability. Once a marathoner and a regular hiker, she felt gradually dissociated and estranged from her body: "My body had always done whatever I asked of it until suddenly it became the most

unpredictable part of my life. [...] From that moment on, I saw my body as a stranger” (ibid., 102). Twenty years after her diagnosis, Lay-Dorsey decided to document her daily life so as to reconnect with her body, turning the camera on herself over the course of five years and weaving the visual narrative of *Falling into Place*, published in 2013. Based on a need to accept her aged and disabled body, these photos create a visual pathography (“a form of autobiography or biography that describes personal experience of illness, treatment, and sometimes death” [Hawkins 1999, 1]) as they give an account of the artist’s individual experience with Multiple Sclerosis (MS).

This five-year project was also prompted by an ethical desire to challenge common (mis)representations of disabled people as courageous and/or pitiable by offering an inside view of the daily life of a woman living with a disabling condition. In this article, I look at some of Lay-Dorsey’s self-portraits in light of Arthur W. Frank’s narrative types of chaos and quest, as defined in his well-known study *The Wounded Storyteller*, exploring how her work combines traits of both categories as a way to eschew such misrepresentations. First, I address the limits of narrative in the face of illness, especially when this experience is chaotic and exceeds words. After reflecting on the chaotic features of Lay-Dorsey’s visual pathography, I explore its underlying quest narrative, following her journey from shame to self-acceptance and connection with others, as enabled by her “communicative body” (Frank 1995, 126).

## 2. Beyond Words: A Narrative of Chaos

Over the course of her debilitating disease, Lay-Dorsey has continuously resorted to art so as to make sense of her experience with MS. At first, poetry was a preferred means of expression and creation of meaning, as she wrote and published extensively in her personal blog.<sup>3</sup> Nevertheless, it was photography that eventually allowed her to “look intimately” at her body and reconnect with it (Lay-Dorsey 2013, 102). Being “tired of words,” as she puts it (Rosenberg 2013), photography became a place for reflection that allowed her to face and accept physical degeneration while documenting the daily life of a woman living with disability.

Indeed, there are certain experiences that are beyond words, verbalization, and narrative. Extreme events, such as physical and emotional trauma, may exceed our frames of reference and therefore disrupt utterance by “bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned,” as Elaine Scarry writes about intense physical pain (1987, 4). The experience of illness, Laurence J. Kirmayer holds, is disruptive of narrative linearity and coherence, as its verbalization is often “fragmentary or undeveloped” (2001, 153); according to Kirmayer, “[i]n illness we have the breaking through into consciousness of non-narratized, inchoate experience that resists narrative smoothing and containment” (ibid., 169).

Furthermore, our perception of a specific event may fall outside the realm of narrativity, as claimed by Galen Strawson. One cannot assume that every human being is “naturally narrative,” since there are multiple ways of experiencing one’s being; in Strawson’s words, “[t]here are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative” (2004, 429). By making a distinction between Diachronic (Narrative) and Episodic (non-Narrative) self-experience, Strawson draws attention to the complexity of self-awareness, criticizing the tendency (and pressure) to achieve a diachronic and narrative expression of events: “the Narrative tendency to look for story or narrative coherence in one’s life is, in general, a gross hindrance to self-understanding” (ibid., 447).

Drawing on Strawson, Angela Woods addresses the limits of narrative in the context of illness and, more specifically, in the realm of medical humanities, questioning “whether narrative should remain the privileged form for the interpretation or restitution” of one’s experience of illness (2012, 75). Consequently, Woods invites us to explore non-narrative ways of materializing this specific experience, contemplating alternatives such as metaphor, phenomenology, and the visual arts which, she points out, “might be useful ‘ways in’ to the meanings of experience generally and of illness specifically, avenues of exploration which might well intersect with or contribute to narrative but do not take storytelling as the starting-point or telos” (ibid., 76).

Rather than simply arguing against narrativity, Woods recognizes the importance of narrative in the context of healthcare as a way to affirm the personhood that is so frequently excluded from a technological and biomedical framework while proposing an appreciation of other expressions beyond the logical linearity of storytelling (ibid., 77). In this sense, Woods is aligned with Kirmayer’s stance that “[n]arratives are important for codifying, representing and remembering experience but there are other knowledge structures which may be more common” (2001, 155). Since they deal with an experience that, as Kathlyn Conway puts it, often “lies beyond our ability to describe it fully in language or to impart to it coherence or expressive form” (2007, 16), materializations of illness and disability should not be limited to a narrative framework, as they often take many different forms – image, sound, movement – that challenge narrative form and exist beyond verbal language.

While viewing Lay-Dorsey’s portraits in *Falling into Place*, there is a specific story that emerges from her visual narrative, a story told by her body in its manifold dimensions: a private and intimate body marked by the passage of time and a disabling illness, a body that is simultaneously disabled and capable, a relational body that interacts with others and embraces its community. Drawing on Frances Borzello, I take these self-portraits, with their intersecting visual and narrative elements, as visual “versions of autobiography, a way for the artist to present a story about herself” (2016, 19).

Based on the belief that “illness calls for stories” (Frank 1995, 54) and on his own experience with cancer and heart attack, the sociologist Arthur W. Frank suggests three narrative categories – restitution, chaos, and quest – in *The Wounded Storyteller: Body, Illness, and Ethics*. According to Frank, these narrative

types arise from the post-modern drive to tell one's story as a way to reconstruct oneself from the "narrative wreck" caused by illness (ibid., 54), while aiming, at the same time, to guide those who listen to illness stories. Defined as "the most general storyline that can be recognized underlying the plot and tensions of particular stories" (ibid., 75), these categories seek to illustrate the ways individual narrators deal with the experience of illness within similar cultural frameworks. Since illness stories will necessarily combine different narrative types, Frank holds, these categories are neither isolated nor separate from each other: "The three narratives are like patterns in a kaleidoscope: for a moment the different colors are given one specific form, then the tube shifts and another form emerges" (ibid., 76).

Described as the "culturally preferred narrative" (ibid., 83), the restitution story takes illness as a temporary interruption of an otherwise normal and healthy life, its plot following the basic storyline "[y]esterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (ibid., 77). Promoted by medicine and reinforced by popular culture, restitution stories are guided by the hope and belief in recovery, being grounded in the idea of a restorable body that proves the success of medical cures. For this reason, Frank states, restitution narratives serve no purpose in the face of terminal and/or chronic illness: "When restitution does not happen, other stories have to be prepared or the narrative wreckage will be real" (ibid., 94).

The chaos narrative, on the other hand, is the opposite of restitution as "its plot imagines life never getting any better" (ibid., 97), being therefore characterized by hopelessness and despair and pointing to vulnerability, powerlessness, and lack of control. Standing beyond speech, chaotic stories are not told, they are experienced, hence lacking sequence, causality, and narrative order. Lay-Dorsey's weariness with words is, in this sense, aligned with Frank's description of the "teller of chaos stories" as a "wounded storyteller" who, unable to tell the chaos in words, tells it through the body (ibid., 98) or, in her case, through the visual representation of her body. As an "embodied form of story," Frank writes, chaos stories are "told on the edges of speech" and "in the silences that speech cannot penetrate or illuminate" (ibid., 101).

As a chronic and degenerative disease, MS fits into the plot of the chaos narrative, not only because restitution to health is – at least so far – not possible, but also due to its unpredictable course; as Arthur Kleinman writes, "chronic illness is an ongoing process in which personal problems constantly emerge to challenge technical control, social order, and individual mastery" (1988, 144). The unpredictability entailed by MS brings about a chaotic lack of control over one's body and life (cf. Frank 1995, 100), the patient being constantly faced with "life's fundamental *contingency*" (ibid., 102), as the writer Nancy Mairs, who also struggled with MS during her lifetime, eloquently put it in her memoir *Waist-High in the World*:

I don't think I am, as the recovery movement would have it, 'in denial' (perhaps because I'll never be 'in recovery'). I feel – and feel fully – the ordinary complement of negative emotions in response to specific triggers: anger and frustration at my clumsiness; embarrassment about my leaky bladder; wistfulness for the

dancing and hiking and cycling I'll never do again; guilt that my helplessness burdens family and friends; anxiety about further deterioration. (1996, 31)

*Falling into Place* displays numerous photos that convey (and cause) discomfort, illustrating Lay-Dorsey's lack of control over her body and the difficulty of getting through activities of daily living such as getting dressed, having a bath, or opening containers. This photo, for instance, depicts Lay-Dorsey's struggle to brush her teeth, her naked body bending over the sink:<sup>4</sup>



Fig.1

This is a mundane, but very private moment, not only because of the task itself, a daily self-care activity, but also due to the location in the bathroom. There is a feeling of frustration and discomfort when viewing these photos, reflecting the artist's own distress while portraying herself in particularly vulnerable moments:

The challenge is that when I look closely at every moment of my day, the emotional defenses I have built up over the years are stripped away. Feelings of vulnerability and shame surprise me with their ferocity. It is one thing to photograph someone else's struggles and quite another to turn the camera on your own. There is no place to hide. I tell myself that any discomfort I feel is worth it because these photographs will give people an inside view of what it is like to live with a disability. (Lay-Dorsey 2013, 103ff.)

This common unease between viewer and subject, teller and listener, is highly evocative of chaos narratives which, according to Frank, are difficult to hear (and see, if I may add) "because they are too threatening" and therefore provoke anxiety (1995, 97f.). As viewers are faced with "the quotidian truths of a body in trouble," as Mairs puts it (1996, 10), they may sense anxiety about their own bodies becoming disabled by means of illness, accidental injury, or age. Generally speaking, narratives of illness and disability cause fear and discomfort because, as G. Thomas Couser comments, they "serve to expose and dramatize what we would prefer to ignore most of the time, to arouse and (ideally) assuage our

anxiety about our somatic selves” (1997, 9). Anne H. Hawkins shares and reinforces this point of view when stating that “[p]athographical narratives offer us a disquieting glimpse of what it is like to live in the absence of order and coherence” (1999, 2).

The private and intimate tone of Lay-Dorsey’s photo is further emphasized by the fact that she is naked, which renders the subject even more vulnerable. Nevertheless, nudity is not the problem here, she claims, as the real challenge lies in exposing the difficulties faced when performing small tasks:

Reflecting back, I realize it is easier for me to show my naked body than to show the reality of what I deal with day-to-day. I am not comfortable letting others see my struggles to open containers, cut up food, get in and out of bed, and pick up the objects I drop on the floor. I particularly dislike being seen when I fall. (Lay-Dorsey 2013, 102f.)

Falling is undoubtedly a fundamental aspect in this visual narrative. First, it is a visible manifestation of MS, showing its unpredictability and the vulnerability and impotence – that is, the chaos – it imposes (Frank 1995, 97). Second, it points to the title of the book itself, *Falling into Place*, an ambiguous phrase that presents something physically and psychologically painful, the fall, as an opportunity to create meaning as everything falls into place and, in a way, makes sense, thus echoing Kleinman’s stance that “[m]eaning is inescapable: that is to say, illness always has meaning” (1988, 144). Finally, let us not forget another dimension of the fall, namely the Fall of Adam and Eve, a rite of passage from a state of innocence to the knowledge of good and evil in which falling stands as a moment that makes us painfully human, yet cognizant of our fragile and precarious condition.

The following photo depicts precisely a fall, more specifically a moment after one of her many falls, as Lay-Dorsey is shown lying on the floor, her legs in the center of the frame, offering a horizontal perspective that allows the viewer to see through the photographer’s eyes:



Fig. 2

The memory of chaos is somehow mitigated by the peacefulness of the photo and by the soft alignment of the legs with the floor, generating a sense of order – as if falling into place. We are once again in a private space, a space that is clean, organized, and serene, every piece of furniture in its right place, the light gently falling on the wood flooring, the presence of Lay-Dorsey’s mobility scooter on the right side of the frame, its sticker “Try Peace” pointing to a more public and activist stance.

Also in the category of images that show her falling, there is a photo that depicts her lying on a red brick paved road, next to her scooter:



Fig. 3

A pre-programmed shot that was interrupted by the artist’s unexpected fall, the image offers us a completely horizontal view, the chaos of Lay-Dorsey’s fall contrasting with the perfect alignment of the frame, the lines of the pavement and the houses converging to her body lying on the floor. As she explains to David Rosenberg, this photo resulted from an accident that happened while she was rushing on her scooter to get a shot at dusk: “Only then did I remember I’d set up a timed shot [...]. I looked at the LCD screen and saw that the frame was in focus and perfectly composed” (Rosenberg 2013).

Falling is, in this sense, an interruption of an otherwise sequential narrative that paradoxically becomes the narrative itself (cf. Frank 1995, 104), since Lay-Dorsey finds her voice in the lived, chaotic experience of her body, in the singularity of her horizontal perspective, what Simi Linton calls “the vantage point of the atypical, the perspectives gained from negotiating a world configured for nondisabled people” (2007, 81). As in *Falling into Life*, an autobiography by Leonard Kriegel about the experience of having his legs paralyzed by polio, falling is transformed into an opportunity to accept a new bodily condition: “For

falling had become the way my body sought out his proper home. It was an earthbound body, and mine would be an earthbound life” (1991, 14).

### 3. Illness as a Journey: A Narrative of Quest

In Lay-Dorsey’s visual narrative, meaning emerges from chaos (that is, falling) as the artist faces her vulnerability and finds in it a vantage point that enables the acceptance of her disabled body. Parallel to this chaos, there is a quest narrative, a journey in which suffering is faced and illness accepted as an opportunity to learn and grow, as Frank describes: “Quest stories meet suffering head on; they accept illness and seek to *use* it” (1995, 115; emphasis in original). The starting point of this journey is represented by a photo of a photo, a meta-photography where Lay-Dorsey is pictured running a marathon, a symbol of strength, overachievement, and physical resistance:



Fig. 4

This portrait crystallizes a memory of a different time – and a different body – prior to MS and therefore in contrast with her current body, here represented by the fragile hands holding the portrait. The dissimilarity between different frames, between past overachievement and present disability, is further emphasized by the partial presence of her mobility scooter in the background, an overlapping of divergent elements that creates a narrative arc where the changes brought about by MS are evidenced. This journey from physical overachievement to degeneration is reinforced in the photo below, juxtaposing a partial view of her legs and bare feet on her mobility scooter with a runner in the background:



Fig. 5

Since *Falling into Place* was prompted by Lay-Dorsey's need to accept age and disability, it outlines a quest in which she strives to reconnect intimately with her body, a difficult journey that began with the representation of her aged body, but not of her physical degeneration: "In my first self-portrait project, I examined the wrinkles that surprised me every time I looked in the mirror. The second showed my body with its sagging breasts and protruding tummy. I did not portray my disability in either" (ibid., 102). In fact, this is the only project that deals directly with Lay-Dorsey's disability and the impact it has on her quotidian, intimate life, as most of her work focuses on Detroit, the city where she lives, and its community.<sup>5</sup>

The artist's quest for self-acceptance and recognition is particularly visible in the following portrait (which is also on the book cover):



Fig. 6

The photo shows a close-up on the artist's upper body, aged and naked; despite occupying most of the frame, we only get a partial view of her body, her hands holding up a mirror that reflects her face. By portraying herself looking in a mirror while simultaneously looking at us, Lay-Dorsey creates numerous angles of reflection and observation, a literal and figurative game of mirrors. First, there is the self-portrait itself, allowing her to create a reflection of herself through photography that instates her as both subject and object. Second, the gesture of looking at herself in the mirror while looking at us reverses the gaze, standing as a performative movement of self-recognition that invites the viewer into the frame, seeing her while she simultaneously sees us and herself.

The face is crucial in this portrait, not only because of its duplication, being partially present in two different points (sideways and reflected in the mirror), but also due to its ambiguous expression, open enough to suggest sadness, introspection, perhaps resilience, thus demonstrating the immense narrative capacity of the face. The idea that the face speaks and has its own meaning evokes Emmanuel Levinas's observations in *Totality and Infinity* (1961), where the face is taken not as a physical or an aesthetic object, but as the living evidence of the "other," a presence that speaks to us and invites us to a relation. As the most exposed and most expressive element of the presence of the "other," the face reminds us of our own vulnerability, instating an ethical relation of love and responsibility for the "other" by making us question our individuality and ability to find meaning within our being-in-the-world (Levinas 1982, 83ff.).

Giorgio Agamben's account of the face is in line with Levinas's, since he refers to the face as "the irreparable being-exposed of humans," an opening that creates a relationship with the "other" and where single individuals open themselves to the communal: "The face is the only location of community, the only possible city" (Agamben 2000, 90). In the same vein as Levinas, Agamben holds

that the face speaks its own language, and that its revelation reveals language itself, though it is devoid of any content itself. According to Agamben, the face “is *only* opening, *only* communicability,” but it is an opening that simultaneously shows and reveals; the face is, for this reason, “the *passion* of revelation, the passion of language” (ibid., 91; emphasis in original). The meaning of the face is utterly dismissive of words, since its discourse is conveyed by its own openness and precariousness. As Judith Butler puts it, echoing Levinas:

The face, if we are to put words to its meaning, will be that for which no words really work; the face seems to be a kind of sound, the sound of language evacuating its sense, the sonorous substratum of vocalization that precedes and limits the delivery of any semantic sense. (2006, 134)

By looking at herself in the hand mirror and in the mirror of the self-portrait, Lay-Dorsey is facing her own alterity, her estranged face and body, while simultaneously inviting us to connect with her as an “other” that reminds us of our own vulnerability. In this sense, the photo represents a moment of self-recognition as she literally comes face-to-face with herself and accepts her body, here symbolized as well by the small sculpture of a sitting torso in the background. Though the absence of a face renders this figure anonymous, the lack of limbs suggests immobility and the wrinkled skin and sagging breasts evoke a body marked by age, which instates the sculpture as another reflection of Lay-Dorsey’s body. As she affirms, this is the body she struggles to embrace in her visual narrative:

I forced myself to take a good hard look at every detail the camera caught and in so doing, I began to accept my disability in ways I never had before. As a photographer, I began to see the outward appearance of how the MS affected my life as interesting rather than negative. And I finally recognized how hard my body works to do everything I ask of it. Feelings of gratitude replaced the feelings of shame that my defense mechanisms had partially covered up for years. I came face-to-face with myself. (Dugan 2016)

Lay-Dorsey’s statement clearly outlines the quest narrative at the core of *Falling into Place*, since illness is seen as a journey guided by a specific “sense of purpose” (Frank 1995, 117), namely the strive to accept her physical degeneration, in which something is gained (the recognition and celebration of her body’s potential). Besides allowing her to face herself, these self-portraits create a distance that enable the artist to look at her illness through a different lens, giving her the possibility to grow into loss.<sup>6</sup>

Depending on its duration and gravity, illness implies numerous losses, having an impact on one’s public and private sphere, altering axes of belonging, reconfiguring the landscapes of the future and changing the horizons of the possible. Serious illness is an overwhelming and disorienting experience, Frank notes, as it entails “a loss of the ‘destination map’ that had previously guided the ill person’s life” (1995, 1). On the other hand, as Hawkins reminds us, illness is also an event that gives us an “inescapable sense [...] of being suddenly plunged into ‘essential’ experience – the deeper realities of life” (1999, 1), meaning that something can be gained (i.e. learned) from the losses brought about by illness. In Kleinman’s words, “[t]he 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” (1988, 144). In spite of living with a chronic degenerative illness that cannot be physically cured, Lay-Dorsey gives an account of her experience in *Falling into Place* that points to what Havi Carel calls “health within illness,” a state that “focuses on experiences of personal growth, adaptation and rediscovery” (2008, 19).

In its difficult acceptance of the physical consequences of MS, Lay-Dorsey’s quest is more than an individual journey, since her gain is meant to be shared with others: “*Falling into Place* not only gave me the tool I needed to integrate my own personal journey, but to help others – both disabled and non-disabled – integrate theirs as well” (Dugan 2016). These words resonate with Frank’s statement about quest stories, namely how they “imply that the teller has been given something by the experience, usually some insight that must be passed on to others” (1995, 118). In this sense, Lay-Dorsey’s visual narrative portrays what Frank calls a “communicative body,” the body that is told in quest stories and which stands as a “pivot point between microcosm and macrocosm,” ultimately bent on sharing with others the personal lessons learned over the journey: “the paradox learned on the quest is that surrendering the superficial control of health yields control of a higher order” (ibid., 126).

Knowing that “contingency is the only certainty,” the communicative body is “open to crisis as a source of change and growth,” an openness that allows it to establish a “*dyadic* relation to others” (Frank 1995, 126). In her wish to share the wisdom found in *Falling into Place* and thus help her viewers to make sense of their journey as well, Lay-Dorsey presents a communicative and dyadic body that seeks connection: “reaching out to others is what the dyadic body does; its desire is to touch others and perhaps to make a difference in the unfolding of their stories” (Frank 1995, 127). Rather than trying to rescue others from their own contingency, the communicative body seeks “to be *for* the other,” to “affect how the other understands her embodied contingency” (ibid. 127; emphasis in original).

This desire to relate and connect is particularly visible in this photo, where we see her dancing at the Detroit Electronic Music Festival:



Fig. 7

A regular presence at this yearly event, Lay-Dorsey is affectionately called “Grandma Techno” by her community, given her love of music and dancing. This portrait shows her in a vertical position, leaning against her scooter, while dancing among younger people, the vibrant colors of her dress matching the vitality of her smile and lively presence. There is a young woman right next to her who is also dancing, generating a contrast, central to the photo, between the artist’s aged body and this vigorous able-bodied woman. This contrast is nevertheless bridged by Lay-Dorsey’s dyadic and communicative presence, on the one hand, and by the common language of music and dance, on the other hand, filling the portrait with joy, color, sound, and movement. This connection through the disabled body, taken not as a problem to be solved, but as a surface of relation, is rather evocative of Mairs’s words: “If I don’t want to be reduced to a constellation of problems, I must imagine my body as something other than problematic: a vehicle for enmeshing the life I have been given into the life of others” (1996, 56).

In her Detroit community – a city itself severely battered by life’s contingencies, such as unemployment, poverty, urban decay, crime, and population decline – Lay-Dorsey stands as a positive role model, her body reaching out to others through music, dance, and the photography she makes and shares in books, exhibitions, and social media (a broader and more democratic means to reach out to others). In spite of this public relevance, and even if her visual narrative reveals several features of the quest story, I do not associate her with the hero of quest narratives (Frank 1995, 119), since the hero is above the human, and therefore another form of dehumanizing and othering the disabled body. Pity and admiration are two sides of the same coin and they both generate distance and estrangement, as emphasized by Mairs: “Admiration, masking a queasy pity and fear, serves as a distancing mechanism [...]. Better to deny the perfectly ordinary

qualities most cripples possess, thus ascribing to them an other, safely remote reality” (1996, 32).<sup>7</sup>

By telling Lay-Dorsey’s story through her atypical horizontal perspective, *Falling into Place* gives an inside view of the lived reality of a disabled body with the aim of deconstructing the tendency to represent and see disabled people as brave, admirable, tragic, or pitiable. Affirming a common humanity and countering the othering of disability are crucial to Lay-Dorsey’s work, as she states:

So many stories of persons with disabilities are told from the outside looking in. Often, we are portrayed as tragic and/or brave, and it is easy to lose sight of our common humanity. We are seen as “other.”

Since being diagnosed with multiple sclerosis in 1988, I have resisted and resented this attitude whenever I encounter it in person, print, or online. In June 2008 I started taking self-portraits with the intention of showing from the inside the day-to-day life of a person with a disability, that person being myself.<sup>8</sup>

Lay-Dorsey’s self-portraits are ultimately empowering as they create a space where her voice may be heard, thus giving agency to a fragile and vulnerable body. As argued by Rebecca Garden, first-person accounts of disability “respond to the call for agency and self-representation expressed by the disability rights slogan: ‘Nothing about us without us’” (2010, 73). In a society deeply grounded in ableism, that is, “the ideological hypervaluation of ableness” (Jarman et al. 2017, 4), mental and physical disabilities hinder the full exercise of one’s citizenship not only in terms of movement and presence in the public sphere, but also in regard to social, political, and cultural participation and representation. As a result, disability is an embodied form of othering that leads to marginalization and exclusion, bringing about silence and invisibility. By concentrating on the disabled body as a subject matter that deserves to be represented and seen, Lay-Dorsey is bent on countering such cultural invisibility by materializing, affirming, and celebrating the non-normative body.

More than aesthetic objects, these self-portraits have ethical implications in their endeavor to share a first-person experience of illness. Visual self-representations, as Borzello comments on self-portraiture, “are not innocent reflections of what artists see when they look in the mirror. They are part of the language painters use to make a point, from the simple ‘this is what I look like’ to the more complicated ‘this is what I believe in’” (2016, 17). The reality portrayed in *Falling into Place* serves, in this sense, the purpose of giving an accurate account of the lived reality and precarious humanity of its author so as to counter misrepresentations and misconceptions of disability, as she affirms: “I am unrelenting in my demand that each self-portrait in this project be an authentic reflection of my day-to-day-life. No constructed fantasies, or exaggerated drama. No wishful thinking or beautified scenarios” (Rosenberg 2013).

#### 4. Conclusion

*Falling into Place* weaves a narrative of interruption and daily struggles, but also of joy and freedom: there are numerous photos at the swimming pool and the

gym, others of her dancing with young people and singing with her husband, Eddie. Lay-Dorsey tells us the story of a body that, despite the chaos it experiences every day, is an able body that is open and capable of giving and receiving, being in community, contributing to the common good, and creating art. By accepting her disability at the end of her five-year journey, she was finally able to familiarize herself with her body and recognize and celebrate its contingent reality:

It may have been an emotional stretch, but taking these self-portraits has helped me see my body for what it is: a warrior, an ally, my best friend. Instead of a stranger, my body is an amazing partner that works unceasingly to help me live the life I choose. Sure, I have to respect its needs and limitations, but in return it gives me the freedom to be myself, my true self. What more can I ask? (Lay-Dorsey 2013, 105)

The words used to describe her body are here particularly significant – “warrior,” “ally,” “best friend,” “amazing partner” – as they challenge the language and metaphors usually employed in the context of autoimmune diseases, in which the body *attacks* itself and is at *war* with itself. There is also a powerful self-affirmation when stating that her body allows her to “live the life I choose” and gives her “the freedom to be myself, my true self,” presenting her as someone who is not a passive victim of life’s circumstances and who therefore shows us, as Frank puts it, “what is possible in impossible situations” (1995, 133).

Neither a hero nor a victim, the woman portrayed in *Falling into Place* embraces her precarious humanity and tries to live her life as best as possible, accepting the limits of her body and celebrating its immense potential: “As a woman living with a disability I know I am neither brave nor pitiable; I am simply doing my best to live a full life with the hand I have been dealt” (Lay-Dorsey 2013, 103). By offering us an intimate first-person account of her experience with illness, Lay-Dorsey’s visual narrative takes us on a journey where great power comes from accepting one’s vulnerability and life’s inevitable contingencies.

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<sup>1</sup> On the narrativity of human existence, see, for example, Bruner (1987).

<sup>2</sup> Narrative Medicine, as defined by Charon, argues that health professionals who possess "narrative competence" (2006, 105-174), acquired through narrative training in close reading and reflective writing, are more effective in their practice as they gain a better understanding of another person's predicament (empathy), are more aware of the meanings hiding behind ambiguity and silence, and become more attuned to the individual as a gateway to the universal.

<sup>3</sup> See [www.windchimewalker.com](http://www.windchimewalker.com).

<sup>4</sup> Permission to use the photos included in this essay was given by the artist herself, Patricia Lay-Dorsey, whom I thank for her immense generosity and kind availability.

<sup>5</sup> There is, for instance, "Detroit: Hidden in Plain Sight," dealing with the paradoxes of this city, simultaneously fragile and resilient; "Detroit's Young Musicians," about one of the largest projects of this kind in the USA; "Active Elders," portraying a group of elderly people who challenge stereotypes about age; see Lay-Dorsey's online portfolio at [www.patricialaydorsey.com](http://www.patricialaydorsey.com).

<sup>6</sup> I am here borrowing Nancy Mairs's words: "I myself would contend that slow degeneration beginning in adulthood offers one time to grow incrementally into each loss and so more easily retain a modicum of composure through the process" (1996, 29).

<sup>7</sup> Mairs explains her preference for the term "cripple" in Mairs (1986).

<sup>8</sup> See Lay-Dorsey's online portfolio at [www.patricialaydorsey.com](http://www.patricialaydorsey.com).