Conceptualising the lockdown from the point of view of chronic illness

Sharon Gallagher and Angie Voela

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In 1989 my body[1] went into lockdown. Since my early childhood and often during my adolescent years, I experienced numerous viral infections treated with antibiotic medications. Whilst working in the US during the early 1980s, I became ill with a non-definable fever and swollen glands, and a few years later with glandular fever. Symptoms persisted. After years of tests and scans, a neurologist diagnosed Myalgic Encephalomyelitis (ME) (Ramsey, 1988). During my hospitalisation I was shocked, not only by the severity of my symptoms, but by that of others. I also became aware of the mismatch between these highly debilitating symptoms and what the media often described as yuppie flu (Tuller, 2007), which perpetuated social skepticism about the reality of the illness and caused frustration for those who care for and suffer with the effects of ME.

Along with relentless weakness and sore muscles, the slightest movement or touch became excruciating. I felt as though I was in a personal prison. Living with a chronic illness, confined at home for long periods of time and often bed ridden, I had to rethink my life, my priorities, my plans, what made and did not make sense, and to organize my space differently. I had to construct a new normal. As a mother of a young child I had to reimagine home as our playground and adventure space. As a mature student I had to reimagine my bed as my study and the sitting room as a place of convalescence. At that time, a long intellectual journey begun. It helped me to find solace in the autobiographical writings of writers and artist who spoke about their suffering and to adopting reflexivity as a way of coping with my illness, eventually leading to research into the lives of those living with ME.

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[1] The experiential part of this chapter is based on Sharon Gallagher's auto-biographical narrative and the lecture she gave as part of the UEL Lockdown Series in June 2020. The theoretical discussion draws on long discussions between the two authors of this chapter. Both authors felt that the speaking *I* should be Sharon's voice.

The 2020 lockdown as confinement at home seemed to present few problems to me; nothing I had not encountered before. Yet, the lockdown reawakened memories which had not been shared or revisited for quite a while and which, up until then, did not seem applicable to so many people. My thoughts on the lockdown, as shared with my UEL colleagues in June 2020, became *an account of one's life* and one's vulnerability. At that time, we all more or less believed that the lockdown was going to be a brief three-month anomaly and things would go back to what they used to be just a short time ago. Questions about the long- term effects of the lockdown, the significant and as yet unfathomed changes in the individual and collective lives, and the demand for change in the socio-political domain were only beginning to emerge. At the same time, confinement indoors was being described as a mixed blessing, both a wonderful opportunity to reconnect with family members and start doing things differently together, and a dystopia where 'our cocoons also become the house of depression' (Capperdoni, 2020).

My experiences of the two lockdowns, my personal one and the pandemic, are loosely and poetically (metaphorically) connected through the signifiers of imprisonment, loss, isolation and time out of joint, and bear witness to what I did in order to re-imagine and, in fact, create a space and a life worth living. My argument is that, like chronic illness, the lockdown can cause us to open and explore aspects of creativity and enjoyment we had not considered before and to connect with others we could not have known, were it not for our common condition. My second argument is that, as with chronic illness, the lockdown can create opportunities to question the discursive and material practices that constitute and determine our living practices. Sometimes closing the door to society may provide time to open up and explore the complex nature of our physical and psychic inhabiting of spaces.

In bed with Virginia Woolf, Marcel Proust and many others

I discovered Marcel Proust (1871-1922) and Virginia Wolf (1882-1941) when I became curious about how others managed to work from bed during illness, as I wrote a lot from bed. I knew little of Proust, and this definitely had to do with my schooling, where any mention of literary names would have been deemed too elitist for East London kids. When I came to know his work, I felt that we all deserved to experience the richness of his language. Proust taught me to experience the world differently, in language, as well as through the senses; to linger on the fine detail, to narrate life indoors. Proust opened up a new way of observing the nuances of life over time that I feel are really important to us as individuals and researchers, the minute and the unseen, which we can only begin to perceive when we open up time to observing and reflecting. And this, I think, is what I am embracing, along with the opportunity to grow reflectively, to really become enriched, in terms of intellectual life.

I was drawn to Virginia Woolf because of her suffering. Like Proust, Wolf goes into the everydayness and the intricacies of life, like the wonders of a moth, to open up the processes and struggles of life and death (Woolf, [1942] 1974). She did suffer but she also communicated to me and others the sense of writing from a place of one's own. Wolf showed me that language is poor when it comes to illness, when speaking of pain. If I described to you my subjective pain, you are not necessarily going to know what I mean. You are going to base your perception on the pain that you have experienced yourself.

In her essay '*On Being Ill'* ([1930] 2008) Virginia Woolf offers a means not to subvert suffering, but to reveal the space of seclusion experienced through illness. As Sim states, 'Woolf offers a means to enter the bedridden world of the invalid' (Sim 2003: 88). Sim further suggests that 'Woolf presents the sick body as a vehicle for knowledge and suggests that common illness poses a challenge to many of our everyday assumptions about self and the world' (Sim 2003:88). Yet, as Woolf notes, experiencing pain can also open up our senses and imagination as it,

> sets us to wait, hour after hour, with pricked ears for the creaking of a stair, and wreathes the face of the absent (plain enough in health, Heaven knows) with a new significance, while the mind concocts a thousand legends and romances about them for which it has neither time nor taste in health ([1930] 2008:102).

The imagination to which Woolf alludes was influenced by her knowledge of Marcel Proust's (1871-1922) *In Search of Lost Time: Volume One – Swann's Way* [1913], in which Proust, described in rich prose, the experience of going to sleep, listening, watching, lying in bed. Proust constructs a colourful cultural tapestry of a middle-class gentleman of his time, almost able to enjoy life from the space of his bed. The pleasure of rest and imagining provide him with a way to enter other worlds and may have little connection to what it means to suffer when bedridden.

> I had only the most rudimentary sense of existence, such as may lurk and flicker in the depths of an animal's consciousness; I was more destitute of human qualities than the cave dweller; but then the memory, not yet of the place in which I was, but of various other places where I had lived, and might now possibly be, would come down like a rope let down from heaven to draw me up out of the abyss of not-being, from which I could never have escaped by myself (Proust [1913] 2014:8).

As with Woolf, we are offered a glimpse of time, space and the imaginary world devoid of social constraints. Proust often presents the bedroom as a refuge, a tranquil space in which to battle the demons of his illness, as he reveals his attempts to recapture his social life through his memories and imagination. Proust and Wolf offer a way to understand how those bedridden may gain power by imagining other worlds. As Roland Barthes notes, Proust and Wolfe described their lives, produced by multiple texts, mutual dialogues and contestations of a shared language, for the reader to recognise and take meanings related to own experiences of living with illness (1987, p144-148).

Another formative influence on my approach to confinement was Frieda Kahlo (1907-1954), who often painted from bed. The self portrait with her spine as a broken column is very difficult to look at but allows one do get a sense of who she is. These paintings helped me and others to understand and express who we were, in pain, as ailing, confined bodies. Frida Kahlo (1907 – 1954) gives one the opportunity to see, think and look at all that is difficult to look at, and to endure that gaze.

Kahlo's visual work eventually led me to the photo-narrations of Jo Spence (1934-1992) and the Cancer journals of Audrey Lorde 1934-1992. Reflecting on living with illness Jo Spence's (1986) auto-visual narration documented her experiences of becoming diagnosed and living with cancer which highlighted not only her bravery, but the body as an 'absolute necessity' (Spence 1986:215). Susan Bell suggests that Spence's visual narrative has the ability to go beyond oral and textual accounts to enlarge and enrich experience (2002:5). Putting herself in the pictorial frame, Spence was able to contest western science's expectations of the passivity involved in being a patient, breaking codes of representation and unmasking the everyday normalized, institutionalised practices associated with the representations of gender and the female body (Bell 2002).

Equally, Audre Lorde's (1980) cancer journals offered me poetic insights into the world of illness and loss, beyond her rich life as a feminist poet and civil and gay rights activist. Lorde notes in her diary:

> I want to write of the pain I am feeling right now, of the lukewarm tears that will not stop coming into my eyes-for what? For my lost breast? For the lost me? And which me was that again anyway? For the death I don't know how to postpone? Or how to meet elegantly? [….] This reluctance is a reluctance to deal with myself, with my own experiences and the feelings buried in them, and the conclusions to be drawn from them. It is also, of course, a reluctance to living or re-living, giving life or new life to that pain. The pain of separation from my breast was at least as sharp as the pain of separating from my mother. But I made it once before, so I know I can make it again. (Lorde, 1980, p.23)

Just like Spence, Lorde taught me the need to translate the silences surrounding illness into language and how poetry can give us back our space: 'the house, the bedroom, the garret in which we were alone, which furnished the framework of our interminable dream' ([1958] 2014, p1), retrospectively returning to places in which we had lived or visited, whilst delving back into the rooms/chambers, exteriorss/interior horrors/sanctuaries of our mind. Writing can offer a means to re-open ways to think and feel, and helps us to make sense of the self during illness or confinement though the art of language.

It was not long after my encounter with canonical writings and photography that I began research into the lives of ME sufferers, including myself as one of the participants. Photo-elicitation allowed me and others to look back at their own images and reengage with the reality and memory of living with(in) long-term illness. The photographic and narrative examples below depict the lives of participants who, like me, had been, or remained, housebound and often bedridden.

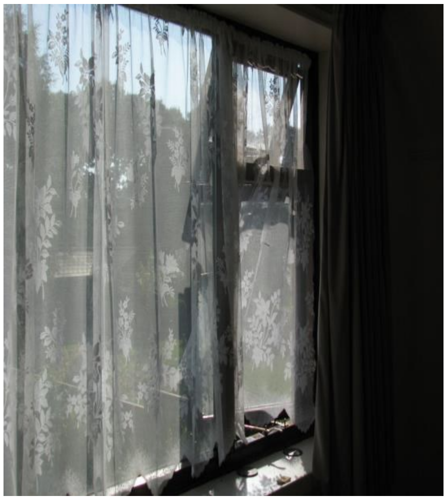

Figure 1

Geraldine is in her thirties and is still living with symptoms of ME:

> That's a window and it sort of sort of representative of […] if you're having a bad day and not getting up and you sort of you tend to see the world from a different view to everyone else, because you know you sort of see the outside from the inside looking out rather than and er you sort of um watch the world going by but you're not quite part of it um you know and I like that shot because it sort of um not that I have a bleak it makes me sound like I'm awfully bleak um the window is bright and the inside is dark erm and its sort of you know it sort of representative of wishing you could get out there things seem a bit dismal inside (Gallagher, 2016, p128).

Geraldine is a visual artist and uses the camera in her creative work. She chose to take the image at a particular angle, using an exposure that seems to amplify the darkness of her room and the light from outside the window. The dankness inside is a comment on her mood. As with Woolf and Proust, the notion of looking and watching is related to a particular kind of listening and waiting. Geraldine has taken the photograph from the viewpoint of her bed as representative of a bad day. It seems to encompass a disconnection from the outside world, as watching 'the world going by but you're not quite part of it' (Gallagher, 2016, p. 128).

Vivienne portrays her untidy spare room as her 'Dorian Gray' space, 'a room you close the door on that nobody ever sees'.

Figure 2

> My spare room or my Dorian Gray room as I call it AND I took the photographs because it sort of akin to how I feel my brain is (-) and my life […] it's all very jumbled there's nothing straight And number one its having the energy with ME and number two having the enthusiasm (-) But I think more importantly than that I it's like hiding your frailties it's that room you close the door on that nobody ever sees, so that's why I took these […] that's a real private thought. I did take another one of my cleared out Dorian Gray room but I've managed to get crap in it again I call it Dorian Gray returns. I think that's a picture of what used to be, that or junk that I don't really use – anymore […] I think it's a place where I'll never go again, I think that's what the point of that is (Gallagher, 2016, p120).

As Vivienne looks at the photograph, she seems to become more of a spectator to her world, with a poignant comment that 'that's a real private thought'. The discarded 'junk' speaks of a sorrowful realisation that this is 'a place where I'll never go again', and frames her present uncertainty. As Vivienne reiterates, her attempts to tidy the room have faltered and Dorian Gray always returns. The discursive style of Vivienne's photo-narrations and the metaphorical expressions that she often used throughout her storytelling convey the continuous *movement* of her illness, explaining in her life story as an 'Archimedes screw' and saying that her brain and life feels 'all very jumbled [and] there's nothing straight' (Gallagher, 2016, p121).

Helen shares a picture of her bed:

> My bed, so that's how I was sleeping because you have the pillows all around, at the sides and under your legs because you're hurting all over, in every joint and in every muscle feels very sore, errrr like last night, the pain in the bottom of my spine, I couldn't cope, it was just unbelievable it was like the worst migraine, along with swollen glands and the symptoms of flu […] (Gallagher, 2016, p125)

Helen's photo-narrations describes the tension between the 'normal' function of the bed and the norms of illness. The photograph highlights the pain of the body, an attempt to make connections with other, more commonly known illness experiences, in her need for others to understand her suffering.

Just like my participants, I had to reinvent the interior of my house, and my bed especially, when my symptoms were extremely severe and I knew I would not be able to do very much at all. I was a single parent at the time, and I had to think how I could play with my son. I used to love running in a park, walking, a champion swimmer. I used to love to be physical, to dance – nothing was there, so I had to think how I could reinvent *it*. At that time *Gladiators* was on television. So, I reinvented that idea, I fixed a hoop and a coat hanger on the door and my son would run in and out and I would scream with delight as if he had won the game, and we would laugh, and this somehow made the bed transient- it was as if it was moving and changing (Gallagher, 2016, p. 216). I didn't have to just see it as a place of rest or being ill. I could see it as a place of physical play.

Language and images open up silences. Unless we speak or write those silences, we will not be heard. What do we need to re-think? What signs are we tracing or following when we go back and forth in our lives? How can we use that insight to develop ways in which we can understand our present? How can we reconnect with a world that will possibly remain shut or partially or intermittently locked down for years to come?

Looking back, I can see that my way or reconnecting with the world and the present pandemic have this in common: they are new, slow, painful but determined beginnings after a catastrophic event, a point after which we become reflectively aware of the fact that the old ways had become unavailable. From that point onwards we are confronted with a formidable choice, to either reinvent both space and time and, in fact, our entire lives, or to succumb to the untold suffering of living in suspended animation.

My discovery of Proust, Wolf and others, which were not part of my formal educational repertoire, bears some resemblance to Bernard Stiegler's discovery of philosophy at the time when, as a young man he was jailed for robbery. Confined in prison, the young Stiegler discovers a *different* world.

Stiegler aligns the lengthy and laborious process of teaching himself philosophy to *anamnesis*, remembering in the Platonic sense. Studying (melete) allows the young man to address his 'forgetting' (both ignorance and the repressed) whilst (re)building a substantial reservoir of academic knowledge (2009: 14). Acquiring knowledge in isolation, then, constitutes the first step towards engaging with the Other, both the abstract philosophical community of which he was becoming part and the world beyond his prison cell. As an intellectual pursuit, philosophy allowed Stiegler to redefine the relationship between self (inside) and space (outside) (2009: 14). The mature man remembers: 'I no longer lived in the world, but rather in the *absence* of the world' (2009: 17). This absence, the disappearance of the world as one knew it in case of illness, inheres a lack which we can only glimpse at significant moments, when, for example, one's inability to cope or know how to live differently can no longer be evaded.

Stiegler reports that his engagement with philosophy gradually effected a change, allowing him to not only progress and learn more but to *interpret* his life, to offer an account and a *hermeneia* (interpretation) which approximates the psychoanalytic sense of the word. Equally important, however, it was the long engagement with the process of learning that created time, duration and space, giving time and place to 'it' which lacked both space and time to come into focus, gradually generating a perspective for making sense of one's life. Boldly, Stiegler admits that when one does not know how to find this perspective, one has to *invent it* (2009: 23, emphasis in the original). This (re)invention of the world, we argue, is a way of opening up the past to the present and the present to the future. Imagining a way forward after the pandemic can then be rephrased as a way of living with/in the pandemic, with the lockdown as a way of producing time/duration and space, here and now.

By the same token, discovering, connecting and in fact creating a community of individuals who share their stories through creative engagement with their symptoms, allowed us to image ways forwards despite our 'predicament'. My participants let me into their world and I let them into mine, both the intellectual, artistic, generous ways of coping, and the messy, hard-to-look-at untidy, dilapidated, unsightly reality of the locked-down body. This, as I hope to have showed in the short excerpts above, is not an easy process. To engage with or after what Winnicott labels as *catastrophe* is said to create an unthinkable agony (Winnicott, cited in Eigen 1999) and might make one feel chained like Prometheus without having journeyed anywhere. *However, becoming* in a relational sense, through learning and creative engagement with others, constitutes a re-organization which chimes with integration and dis-integration and ultimately sets free and liberates.

Of course, the lockdown comes with restrictions imposed from outside, and, as we shall see below, restriction which can best be understood with reference to power. The chronically ill and those in lockdown are experiencing and have experienced similar issues of being closed off from society, as we all hold dual citizenship between the land of the well and the sick (Sontag [1979] 1991). With the advent of digital technologies, we seem to be policing each other a lot more systematically, and private lives and movements are being constantly monitored by health and government institutions in ways that can be almost intrusive to the internal space (Lupton, 2020; Will, 2020). Equally, the language adopted during the lockdown bears similarities to chronic illnesses, replete with militarised metaphors of war, rooted in the need to pathologise and defeat death (Sontag, 1991; Blackman & Walkerdine, 2001) and the proliferation of negative aggressive connotations and measures connected to the pandemic, joins forces with the advance guidance and restrictive access reserved for the chronically ill (Will, 2020).

These facts of pandemic and illness governmentality should neither be overlooked or ignored, but to these aggressive and phobic reactions we need to respond with the creative, poetic and relational approaches that start here and now and extent to the future. Even if the lockdown ended right now, we would still have the arduous task of making sense of our experience. So far, the focus seems to be on functionality and productivity to achieve economic sustainability rather than on spatial challenges effected by the merging of personal spaces with institutional spaces, such as workplaces, classrooms and wards. None of these are self-evident, and silences need to be replaced by language and a relational becoming that could give *form* to our experience[2]. The additional challenge is to do so with others, creating and sharing a common language instead of being

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[2] By giving form to experience and the psychic structural change this might imply, see Voela and Rothschild 2018.

inarticulate, yelling at one another, for example, for not wearing a mask, or beating a retreat at the thought of bodily proximity (Blackman & Walkerdine, 2001).

Spaces of crisis, spaces and crisis?

I wish to turn briefly to the concept of space. Social space can be a matrix of historical, geographical and cultural properties, discursively maintained through social systems which territorialise the productions, limits, meanings and perceptions attached to space (Lefebvre, 1991). These public and private spaces normally have visible boundaries which separate them and which are further replicated inside the private domain, separating, for example, the bedroom from the study with barriers which close off their social functions (Lefebvre, 1991, p. 134). As subjects we develop attachment to demarcated spaces. Thus, for Foucault, as for Lefebvre, spaces are not real but relational, containing social and cultural codes that regulate contact and behavior (Foucault 1998: 177).

Foucault invites us to reconsider spaces which we often think as neutral, such as the house, in terms of the powers which control and shape them (Foucault 1980:146), further indicating that the very same spaces may operate as places of contestation of normative practices. This contestation is best articulated by the concept of heterotopia, introduced by Foucault in *Of Other Spaces* (1984:48), a contemplation of spaces which exist side by side with ordinary ones but can accommodate deviance, crisis or change. C*risis heterotopias and heterotopias of deviation,* Foucault notes, are adjacent to but also juxtaposed to ‘ordinary’ social spaces. They are often guarded or having regulated access which protects their integrity. Heterotopias can be spaces of active imagination and becoming, as was the case of the 19th century teacher training colleges for women (Tamboukou, 2003), or spaces in which women are able to temporarily withdraw and ‘lay down the baggage of the unconscious’, preparing themselves for a less encumbered future (Voela, 2011). I have shown elsewhere (Gallagher, 2016) that the house of the chronically ill can be a heterotopic place, which transcends illness and breaks down the socially determined uses of interiors.

The lockdown gave rise to a similar kind of heterotopism but was quickly superseded not to say invaded by a different manifestation of power. Initially heterotopic, the quarantine guidelines prescribed a certain amount of regulation of movement and permission to enter or leave. This, in turn, established a transient space-time, allowing us to 'enjoy' home so long as we are not deviating from the normative rules of lockdown governing the public realm. Under the circumstances, it is possible that we may experience our own homes as heterotopias of crisis where, apart from regulated passage, our bedroom became a study, a school or a workplace, and all rooms became messy and untidy. At the same time, however, we begun to feel, all the more acutely, the regulatory power which descended upon our homes, carried over by the highly prescriptive language and imagery of hygiene and social distancing. Just like the chronically ill, we may have felt confused in trying to both conform to the medical discourse and maintain a space of our own.

We may have also become aware that systems of control are not addressed to a universal subject but are made up of various networks of power and social stratifications linked to educational, class, ethnicity and generational issues. A new phenomenon entered our living spaces: the house-to-house and inside-to-inside relationship, in lieu of an outside. With the advent of Zoom the viewer is now privy to the once private spaces of many, with bookcases becoming the new 'window' to one's persona. This may suggest that once liminal or private spaces are fast becoming the means of identifying each other, with as yet unquantified consequences for our perception of identities. A recent article, for example, entitled, 'The ridiculousness of the bookshelf police' decried Michael Gove as being racist due to a book on holocaust denial (O'Neill, 2020). Consider also the chancellor, Rishi Sunak, appearing before his own bookcase.

UK Chancellor Rishi Sunak speaks in front of his minimal modern bookshelves (Heathcote, 2020).

Presumably, the politician Rishi Sunak had to present himself as calm man in control during these difficult times but as viewers we could not help but explore the fronts and spines of the books on his shelves in the hope of finding out more about the man at the center of the screen.

But what is missing from these perfect displays of knowledge and power? I argue that it is the messy reality of illness and the lockdown, the crowded rooms, the untidy spaces, the Dorian Grey cupboards, the windows which evoke an outside, not another inside, the very *reality* of living. When I delivered this lecture to my colleagues, I would have liked to have sat in my living room, in front of my own bookcase, with all my favorite Proust books on display. But my mother, who is recovering from Covid-19 and now lives with us, now uses the living room as her bedroom. In some households there is little room for vanity.

Concluding remarks

The lockdown was initially spoken about as a passing crisis, with most people feeling they were wasting invaluable time to being locked indoors. The chronically ill would like to remind them of the protagonist of *Shawshank Redemption* (1994), the lawyer Andy Dufresne who, though wrongfully convicted and diligently working on his escape, did not fail to build a life in prison, thus renouncing both the fantasmatic narrative that life is only ‘out there’ and refusing to be institutionalized to the extent of being unable to ever live outside prison (Žižek, 2000, 148). By the same token, losing time to being confined indoors through no fault of one’s own may lead to a re-affirmation of life when trauma or irreparable loss is brought down to measure. Beyond loss, a reinvention of one’s own can only be relational and accomplished with the various others with whom we share something of our *sinthome*, that is, our unique way of sidestepping the dominant economy and heeding our own desire (Ruti, 2012). This new mode of living has its darks and illegible days but also carries the conviction that it is not isolation that divides, separates or keeps us apart.

From a Foucauldian perspective, the lockdown can be seen as a critical junction between new and old regimes of subjectification and contestation. The lockdown gave us two bodies (Burnham, 2020), a real and a virtual one:

> Our virtual body, which lags behind overburdened VPNs and is distracted by social media, then splits off from our organic body, which simultaneously attempts to do child-care, monitor our own temperature, wipe its ass with stockpiled toilet paper. Those who do not have two bodies – the workers who cannot work remotely (cleaners, mechanics, delivery persons) are then those who suffer (Burnham, 2020).

Indeed, and again chiming with chronic illness, the real body suffers and desires to be free of pain and, perhaps, to be virtual. But, at the same time, it revels at the messiness of everyday living which undermines fantasies of orderliness and perfection arising with the 'new normal'. In order to maintain this as a permanent mode of subversion, we need both a theory of space (as in Foucault) and the keenness to look awry (as in Žižek) for what is missing from a perfect picture, allowing absence and loss to always return and find a place of their own.

Chronic illness teaches us how to endure time and to bear varying temporal segments (day and weeks when one feels weak) without turning crisis into despair. It has been claimed that Covid-19 constitutes a crisis the meaning of which should be sought not only in the linguistic duality of *krisis* (decision) and *krinein* (to decide) in its Greek root but also in the resonances of late Middle English, where the word comes to mean *the turning point of a disease*, that *decisive* point at which the condition of the patient manifestly *improves* or *deteriorates* (Gandesha, 2020, emphasis added). For us the challenge remains: consider a condition which improves and deteriorate ad infinitum – and contemplate living with it.

With the above in mind I would argue that, like chronic illness, the lockdown can be enjoyed. Not with the abandon of the melancholic who unburdens herself of a harsh superego in from of the impending planetary disaster (see Von Trier's Melancholia) or with the excitement of giving in to jouissance (enjoyment) at the face of imminent death (Burnham, 2020) but with learning to make the most of the moment. I am thinking, in particular, of crowded households where we need to continue inventing and feeling our own presence. For some this may be difficult, if not impossible. If you cannot find a place, you might be able to find a moment; a moment within the disrupted spaces to create, to write, to draw, to take a photograph of your world. Look around and write about the moment when the kids are asleep, watch the wind, listen to a dog bark or a fan blow, feel your fingers touching each key on the keyboard, in response to typing these words, pause and think: I'm touching, I'm seizing the moment. Carpe Diem.

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