



Breathing Life into a Phenomenology of Illness, Part II

Havi Carel on understanding illness through its lived experience

Part I can be read [here](#).

What is breathlessness? This is a seemingly simple question. Why, it's the well-known experience of panting, perhaps getting hot and sweaty, maybe a heaving of the chest, or a slight aching around the ribs, or an urgent need to breathe through your mouth and not just nose? Everybody gets breathless when they exercise or run for the bus. Everybody knows what it's like. Not so simple. In fact, breathlessness is far more complex and far less understood than it seems.

Breathlessness is also a very common symptom of a wide range of respiratory and cardiac disease, as well as other disorders such as panic attacks and disorders of chest muscles. As such, it affects a huge number of patients around the world. Indeed, chronic obstructive pulmonary disease (COPD), which is characterized by progressive and debilitating breathlessness, is estimated to become the third leading cause of death globally by 2020. According to improving and integrating respiratory services (IMPRESS), 25% of attendees to emergency departments, 62% of elderly people, and around 95% of people with COPD report breathlessness. It is a strong predictor of mortality, and very common in the end stage of many diseases.

Prima facie, breathlessness seems like a simple bodily sensation. In fact, it is multi-faceted and incorporates several sources of input, such as oxygen saturation level, respiratory effort, chest muscles work, and blood pH level. In severe desaturation, feelings akin to suffocation, dizziness, sense of loss of control, and incontinence are often present. Overall, the sensation is one of acute unpleasantness and distress, but not of pain as we normally understand it.

Recent work in the neurophysiology of breathlessness shows that the same brain pathways are activated in breathlessness as are in pain, hunger, and thirst. This may lead us to explore the possibility that breathlessness bears a family resemblance to pain, but is not analogous to it. It also makes salient the need for a phenomenological analysis, which may reveal how the

experience of breathlessness is similar or dissimilar to other unpleasant sensations such as pain, hunger, and thirst.

Breathlessness can be experienced with or without other symptoms such as oxygen desaturation, hyperventilation, dysfunction of chest muscles, and dizziness. It may be that the breathlessness experienced in an asthma attack, in which the airways are suddenly narrowed, is different to the experience of breathlessness in COPD or heart failure. Currently, the term 'breathlessness' is used in both medical and lay language to cover a vast array of medical conditions and their associated experiences. It is not clear that the term is precise enough, nor that it captures the complexity of the experience.

It is unfortunate that we use the same term—breathlessness—to cover both normal breathlessness, experienced on exertion, and pathological breathlessness, triggered by minimal or no effort and which is debilitating. Do the two sets of experiences overlap? Do they have shared features? Do they lie on a continuum or are they phenomenologically distinct? How to people who focus on their breathing (what we might call 'aware breathers') come to experience breathlessness? Can particular breathing practices, such as meditation, singing, playing musical instruments, and sports teach us anything useful about breathlessness? Can we compare 'aware breathers' who are healthy with those who become aware of their breathing due to a pathology? Clearly, there is phenomenological work to be done in this area, both philosophically and empirically.

Breathlessness is a common symptom, but it is also unique. Unlike many other medical symptoms, breathlessness (and breathing) has complex and powerful psychological, cultural, and spiritual dimensions. We 'take a deep breath' to calm ourselves; we are invited to 'inhale deeply' the fresh air in the countryside; a remarkable artwork 'takes our breath away'. Breathing is deeply and intimately connected to, and reflective of, our state of mind, feelings, mood, and sense of wellbeing. That is why breathing is central to many spiritual practices such as pranayama, meditation, and some religious practices, especially in Eastern religions. When one is anxious or frightened, breathing becomes fast and shallow. Panic attacks are often accompanied by a fear of being unable to breathe, and the fear of suffocation that follows exacerbates the attack. In short, both normal and pathological breathing are complex phenomena, with many levels of expression and a multifactorial physiological, psychological, and spiritual/cultural underpinning.

Phenomenologically speaking, breathlessness is remarkable in two intertwined ways: it is an overpowering sensation, which we are deeply sensitive to, but it is also behaviourally subtle, and so often invisible to others. Even we ourselves are not always aware of when we start to become breathless and why. Techniques like meditation and mindfulness training help practitioners become more aware of their breathing, but this is hard to do when one is immersed in an activity and one's attention is turned away from oneself. This phenomenon has led Gysels and Higginson (2008) to coin the term 'invisible disability'. The Janus-faced duality of breathlessness—the fact that it is so real and overwhelming to the person experiencing it and yet so invisible to those around her (and, in particular, to health professionals)—merits close analysis. I suggest that breathlessness is phenomenologically salient for the reasons given above, and that a phenomenological analysis may reveal facets of this symptom that have hitherto been unrecognized or that have been obscured by a physiological analysis of the symptom.

So what is the experience of severe, pathological breathlessness like? Here are a few passages from *Phenomenology of Illness*:

Trapped. That is what breathlessness feels like. Trapped in the web of uncertainty, bodily doubt, practical obstacles and fear. The deepest fear you can think of. The fear of suffocation, of being unable to breathe, the fear of collapsing, blue, desaturated to the point of respiratory failure. Even if illness descends upon you gradually, over many years, there comes a point—probably around the '30% of predicted' mark—where high spirits and positive attitude just can't cut it anymore.

You are faced with the shrinking of your world, choices, freedom and eventually, your spirit. Our embodiment determines our possibilities and delineates with extreme clarity what one is and is not permitted to do and be. The spirit is tethered to the body and its limitations cut deep into spiritual life. Transgressions are punished harshly. Push yourself too hard, and you will pay. Pay with nausea, with dizziness; pay by passing out, collapsing in front of strangers, or worse, in front of loved ones.

What is the phenomenology of this total sensation? Like pain, you cannot ignore it under any circumstances. You might try to pretend outwardly, but on the inside, the sense of loss of control—and the secondary fear of that sensation—will keep you tethered to your oxygen tank, and reluctant to go anywhere where your oxygen arrangements might be compromised. The psychological impact is enormous. The sense of bodily doubt and insecurity gives rise to a host of psychological reactions: despair, fearfulness, anxiety, depression, loss of hope. Respiratory illness is a life sentence with no reprieve, no parole board, no early release.

The world shrinks and becomes hostile. The sense of possibility that accompanies objects disappears. A bicycle is not an invitation for an afternoon of fresh air and freedom. It is a relic of days bygone. Hiking boots now sit leaden in a cupboard. They are no longer ‘something to be worn when going for a hike’; they have long been too heavy and hiking too hard. The inviting smell of mud and hills has faded from their soles, but you cannot find it in your heart to give them away. That would be admitting the finality and irreversibility of your condition.

The physicality of every action needs to be calculated, considered, configured to suit your body’s limitations. You now sit on the floor to receive the slobbery kisses of your toddler. Groceries have to be judged by their weight. Strolling along on a beautiful summer day is censored by the gradient, amount of oxygen left in the tank, temperature and fatigue. Everything becomes potentially debilitating, frustrating; a problem.

I recently started to think that chronic and debilitating breathlessness of the kind described in these passages is a **transformative experience**, to use Laurie Paul’s term. A transformative experience is an experience that changes you deeply in significant and lasting ways, both epistemically (teaching you new things through having new experiences) and personally (changing your priorities and preferences as a result of having new experiences). I suggest that severe breathlessness changes the breathless person’s psychology, horizon of possibility, sense of trust, capacities, and embodied subjectivity. It transforms the breathless person’s relationship to her world, to herself, and to others. It changes how she views herself and what sense of agency, possibility, and physicality she comports herself with. In future work (jointly with Ian James Kidd), I plan to explore in detail the proposition that breathlessness is a transformative experience. But for the time being, I hope this blog has given you a taste of *Phenomenology of Illness* and—yes—now is the time to stretch and take a deep breath.

*Havi Carel is Professor of Philosophy, University of Bristol. This essay is based on her new book **Phenomenology of Illness** (Oxford University Press, 2016). Her research is concerned with issues in the philosophy of medicine, phenomenology, and the intersection between the two.*

Image credit: Jessica Lloyd-Jones, **Electric Lung 2008**

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