

THE ART OF LIVING SERIES

Series Editor: Mark Vernon

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ACUMEN

In the hope that some healthcare practitioners will be reading the book, I make some suggestions along the way about how a phenomenological approach could inform their important work. There are some practical suggestions on how a phenomenological approach could be incorporated into current healthcare practices and how the patient's point of view could be made more relevant and informative.

In what follows, I share personal experiences and insights in the hope that these will illuminate the philosophical ideas discussed here as well as demonstrate the importance of the first-person perspective. I describe real encounters but names and details have been changed to avoid identification.

When I speak of illness in this book, I refer to physical illness. Since I have no experience of mental illness, I thought it prudent to limit myself to physical illness. This is not to deny the importance of mental illness or the suffering experienced by those who are affected by it. I also make few references to disability (unless speaking about my own disability). Again, this is not to deny the significance of disability, but to avoid speaking on behalf of people who may be affected by different matters. I presume that there is some overlap between the three conditions and that my analysis may be relevant to mental illness and to disability, but I make no claims about either.

I am not claiming for a moment that my experiences are universal or even similar to those of others. I share them in the hope of making illness a little less scary, less anonymous, by talking about what happened to me. It is my hope that illness, a near universal event affecting almost everyone, will be illuminated anew on viewing it from a phenomenological stance.

1. The body in illness

It is Christmas 2004, the height of summer in the southern hemisphere, and I am in New Zealand. My friends and I are on holiday, touring the South Island for two weeks. Part of our trip is a three-day coastal walk. We are walking towards the farm we are staying in on the Eastern coast. On the way we see dolphins and seals and wood pigeons. The air is fresh and the scenery beautiful. I am eager to hit the trail and confident because I have been exercising a lot lately and feel fit and full of life. I have become a health freak, eating little fat, spending forty-five minutes a day on the Stairmaster and lifting weights. I bounce and walk forwards, happy, energetic, bursting with joy. We walk at a brisk pace, chatting and enjoying the views and the sunshine.

The terrain changes and we are now walking uphill. Suddenly, things become difficult for me. I lag behind; I can no longer chat to my friends. I stop and pour out the water I am carrying. Perhaps I am carrying too much weight? I try to walk on, but something is slowing me down. I have to stop frequently to catch my breath. No matter how slowly I walk, I still have to stop. The trail that seemed so inviting and beautiful is now harsh and endless. Eventually, I lag almost an hour behind the group. My sister-in-law, Mona, is keeping me company. She stops with me, pretending she wants to look at the views. I am worried: how could I be so unfit? Why isn't my body responding to all the exercise? I thought I'd be leading the group, but instead I am soon labelled the slow one, the struggler.

In the months that follow my husband and I invent a string of explanations for my breathlessness. Maybe my lungs are small? Perhaps I have asthma? Maybe I have a tiny chest infection? I return to the gym with greater ferocity and determination than before and sign up to an additional kick-boxing class. I don't go to the doctor, and will not do so until two years later, when my inability to breathe has become so prominent and abnormal that these feeble excuses no longer seem reasonable. But the sense of uncertainty, the struggling, the inability to understand my own body's responses, have been constant companions to me since.

The betrayal of the body, the increasing alienation from her body that an ill person experiences, is the main focus of this chapter. So how is the experience of an ill body different from that of a healthy one? The phenomenological approach of Merleau-Ponty provides a fascinating account of this difference. It is Merleau-Ponty's emphasis on perception and on the centrality of the body to human existence that I find particularly compelling in relation to illness.

Merleau-Ponty sees the body and perception as the seat of personhood, or subjectivity. At root, a human being is a perceiving and experiencing organism, intimately inhabiting and immediately responding to her environment. To think of a human being is to think of a perceiving, feeling and thinking animal, rooted within a meaningful context and interacting with things and people within its surrounding. By taking this approach, Merleau-Ponty responds to a previous, intellectualist (as he calls it) definition of the human being provided by the seventeenth-century French philosopher René Descartes (1596–1650). Descartes defined us as thinking, abstract souls who temporarily and contingently occupy a physical body. Descartes's approach is known as "dualism" because it postulates two different substances: spatial or extending substances such as physical objects, and thinking substances such as minds.

Merleau-Ponty's aim was to correct this erroneous view and, while avoiding the materialist reduction of mind to matter, to

emphasize the inseparability of mind and body, of thinking and perceiving. His approach can be thought of as holistic with respect to the human being. We cannot divide a person into a mental and a physical part, because the two are *de facto* inseparable. Any mental activity must have some physical action underlying it (for example, some neuron firing in the brain). It is impossible, on Merleau-Ponty's view, to think of a purely mental action because mental activity, abstract as it may be, is always embodied. Additionally, for us to acquire abstract notions and concepts requires experience of the world. So, for example, our concept of the colour red arises from coming into contact with red objects, seeing and touching them. The concepts arise from sensual, perceptual experience. If we take these two arguments together, we can see the grounds for Merleau-Ponty's claim that there is no mental autonomy in the strict sense.

Similarly, physical action cannot be seen as mechanical manipulation mysteriously governed from a distance by mental commands. The body is not a passive container or vehicle simply awaiting instructions from the mind. Nor is it a system of pulleys and levers (as seventeenth-century mechanistic philosophers thought) that only comes to life when infused with a soul. Rather, it is an active entity, constantly taking in information from the environment and aiming at various goals. The separation between mind and body does not make sense. Moreover, the strict separation between an internal realm and an external world does not make sense when we think about how we actually experience our body and the world, as a seamless unity.

Instead of artificially separating mind and body, Merleau-Ponty pointed to the centrality of the body and how the subject inhabits the body. This more organic and biological view of the human being as a human animal (which also has culture, sociality and a meaning-endowed world) sees the body as the seat and *sine qua non* of human existence. To be is to have a body that constantly

perceives the world through sight, touch, smell and so on. As such, the body is situated and intends towards objects in its environment. Human existence takes place within the horizons opened up by perception.

Thus for Merleau-Ponty the body is a body-subject and engages in a "primordial dialogue" with the world. This dialogue is pre-reflective, absorbed engagement with the environment, which can be easily understood by thinking about everyday activities. For example, going for a walk is such a dialogue of the body with the environment: the legs propel the body forwards, the labyrinth in our ears keep us upright and balanced, the eyes provide visual information about the path ahead and any obstacles to be negotiated, and so on. This kind of dialogue with the environment requires the constant taking in of information and constant recalculation of route, speed and muscular effort.

A second dialogue takes place between different body parts and types of information. This synthetic activity unifies the information coming from the eyes, legs, muscles and so on to create a unified experience of walking. The whole time this complex interaction takes place, the walker could be avidly discussing Nietzsche, paying no conscious attention to her body. This does not make her disembodied, and does not bring back Cartesian dualism. It simply shows that embodiment is a background condition for a realm of subjectivity to exist. This holds true even if no attention is paid to the body. Whether playing tennis or working out a mathematical problem, both activities, and the whole spectrum in between, are possible only in virtue of having a body, existing as embodied in a world.

Many of our actions, particularly everyday routine actions, are pre-reflective: they are the product of habit rather than conscious reflection. A complex web of such habits makes up our behaviour. Our habits and ordinary ways of engaging with our environment create a familiar and meaningful world. Against this often implicit

background activity, reflection and conscious thought take place. Normally we pay attention to what is consciously preoccupying us at a given moment, for example, thinking about a philosophical problem, rather than about the cup of tea we are preparing while thinking. But Merleau-Ponty wants to focus on the significance and sophistication of this background and moreover to understand how it enables conscious thought to take place on top of it, as it were.

The body is the centre of his investigation. It is a unique kind of object for Merleau-Ponty. The body is, of course, a physical thing, an object that can be weighed, measured and described using purely physical or naturalistic terms. But it is also the source of subjective feelings, perceptions and sensations, the seat of subjectivity, and consciousness. As such the body is a subject-object, a unique being that can be experienced both from a third-person point of view (we look at other people, measure their height, observe their eye colour) and from a first-person point of view (I feel myself sitting on the chair, I am thirsty, I stretch my arms and experience my muscles distending and releasing).

Merleau-Ponty uses the simple example (from Edmund Husserl's *Cartesian Meditations*) of two hands touching each other. Each hand is both touching, active, sensing the other hand, and also being touched, passive, being sensed by the other hand. It is this view of the body as being both an active touching subject and a passive touched object that reunites the mind and body, the first- and third-person points of view, after centuries of separation following Cartesian dualism.

In this intense focus on the body, Merleau-Ponty develops the notion of bodily intentionality. Intentionality was originally conceived by Franz Brentano and Husserl as a relationship between mental phenomena and their objects. It is the relationship of being *about* something, or intending *towards* something. For example, if I wish to eat ice cream, ice cream is the intentional object of my wish.

Interestingly, only mental phenomena are intentional, or *about* something. Wishing for ice cream, believing that my bicycle is in the shed and so on, are examples of intentionality towards ice cream and bicycles. Every mental act such as wishing, believing, desiring and so on, must be about something, or in other words must have an object. Thoughts are *about* something, beliefs and desires are *about* something, but physical objects cannot be about anything. Physical objects are not mental phenomena and therefore lack intentionality. A shoe cannot, in principle, be about anything. This feature of "aboutness" is often regarded as the defining mark of the mental.

Merleau-Ponty took on board the idea of intentionality but refused to accept that only mental phenomena can have this property of intentionality or "aboutness". He extended the notion of intentionality to include bodily intentionality. This is the body's intending towards objects, directing itself at goals, and acting in a way that is "about" various aims and objects. For example, if I reach with my hand to grasp a cup of tea, my hand intends towards the intentional object, the cup. The position of the hand, the direction of the movement, the arching of the fingers are all directed at, or intended towards, that cup.

An intentional arc, as Merleau-Ponty calls it, connects my body to the cup of tea. This intentional arc makes sense of a collection of disparate bodily movements, unifying them into a meaningful action: intending towards the cup of tea. In this sense we could say that bodily intentionality is an analogue of mental intentionality. Some philosophers make the stronger claim that bodily intentionality is primary to and the foundation of mental intentionality. They claim that there can be no mental intentionality without bodily orientation in a world: that there is no purely mental intentionality.

What are the implications of this bodily intentionality? This notion serves to explain the body as being an intelligent, planning

and goal-oriented entity. The body is not a passive material structure waiting for mental commands, but rather is actively engaged in meaningful and intelligent interaction with the environment. The body *knows*, so to speak, how to do many things, how to perform minute and complex actions, how to achieve a plethora of goals from ice-skating to driving a car. Through its directedness the body executes actions that are not merely random physical movements, but intentional, planned, goal-directed movements. Moreover, the movements only have meaning when understood as aimed at a goal. "For us the body is much more than an instrument or a means; it is our expression in the world, the visible form of our intentions" (Merleau-Ponty 1964: 5).

The body responds to the environment in an ongoing dialogue. Everything else depends on the body's ability to perform, predict and react appropriately to stimuli. Thus the body is the core of our existence and the basis for any interaction with the world. "The body is our general medium for having a world" (1962: 146). All our actions and goals have to be rethought in light of this new role accorded to the body or, more accurately, new recognition of the role that it was playing all along.

The ill body

Having seen how central the body is to any notion of agency or subjectivity and to achieving any goal, we can now ask what happens when the body loses some of its capacities and becomes unable to engage freely with its environment. In illness, and more pointedly in some cases of chronic illness and disability, we find a need to rethink the body's ability to engage with the world, its ability to provide movement, freedom and creativity as it did before.

So how should we think about illness? If we go back to Merleau-Ponty's view of the body as both object and subject, the *ambiguity*

of the body, as he calls it, we can see an important angle exposed in illness. This is the difference between the biological and the lived body. The biological body is the physical or material body, the body as object. The lived body is the first-person experience of the biological body. It is the body as lived by the person. Normally, in the smooth everyday experience of a healthy body, the two bodies are aligned, harmonious. There is agreement between the objective state of the biological body and the subjective experience of it.

In other words, the healthy body is transparent, taken for granted. We do not stop to consider any of its functions and processes because as long as everything is going smoothly, these are part of the bodily background that enable more interesting things to take place. So while digestion, fluid balance and muscular performance are going well, we do not experience them consciously. They silently and invisibly enable us to compose symphonies, have coffee with friends and argue about politics.

It is only when something goes wrong with the body that we begin to notice it. Our attention is drawn to the malfunctioning body part and suddenly it becomes the focus of our attention, rather than the invisible background for our activities. The harmony between the biological and the lived body is disrupted and the difference between the two becomes noticeable.

We can also think about the body in analogy to an instrument or a tool. Take a pen, for example. We normally use a pen to perform a task, say, to write a cheque. While using the pen, we do not notice it. It is inconspicuous, a means to an end. Our attention is focused on the end – writing the cheque – while the means are uninteresting and relegated to the background. But when the pen fails to write – the car refuses to start, the milk bottle is empty – it suddenly becomes the centre of attention. It ceases to be an invisible background enabling some project and becomes a stubborn saboteur instead.

This inconspicuousness holds true for tools and even more so for our body. Whereas we can throw out the useless pen and grab another, our body stands in a very different relation to us. Our body cannot be replaced, thrown out or even repaired as readily as we would like it to be. My head with a headache remains attached to me, and becomes increasingly conspicuous, increasingly disabling. It is precisely *because* our body is not a tool that its dysfunction is so important, so intimately linked to our well-being. Whereas my malfunctioning car can be sold and a new one bought, my body *is* me. This is an essential feature of our embodied existence that is brought out by illness. Illness is an abrupt, violent way of revealing the intimately bodily nature of our being.

Another reason the difference between the biological and the lived body emerges in illness is that the lived body is in large part habitual. It is used to performing certain tasks at a certain speed, in a certain way. Think of the way you do something that you do routinely: shave, play tennis, chop vegetables, sew, play the piano. These actions can be performed expertly, efficiently, smoothly, because they have become habit. Our body learned to perform them and with each repetition the habit is reinforced, incorporated further into our bodily repertoire. We may perform some actions with little or no attention. Again, the actions are harnessed to the goal of the activity: getting to work, a cooked meal, an ironed shirt. It is only when we watch a novice, say, a child learning to ride a bicycle without stabilizers, that we appreciate the difficulty of the activity and the level of expertise our bodies have acquired.

Our everyday activities rely on the interplay between the body as it is experienced now and the habitual body. The habitual body provides the framework, the expertise, while the body as it is experienced now provides instant feedback from the environment, different sensations, feelings of satisfaction and so on. Our expert bodies are the product of many years of habituation and practice. The practice can be conscious and structured, as in taking dance

lessons or driving instruction, or unstructured and spontaneous, as in children's play.

This acquired expertise, the effortless ease with which we perform habitual tasks, relies on two things. One is the continuity of the experiencing subject. The same person who learned to play the piano as a child is now playing Mozart's Fantasy in D minor. Memory and continuity are essential for maintaining personal identity over time. The second is that the actual capacities of the biological body remain intact. These physical capacities underlie any attempt to rehearse or master new skills. A common example would be that of an adult attempting some childhood feat, such as a somersault or back dive that they used to perform as children. If she is out of shape, if her muscles and flexibility are no longer as good as they used to be, the habitual body will encounter the resistance of the biological body. The habit may still be there, but the biological body has changed and is no longer cooperating with the ease and agility it once had.

Another example given by Merleau-Ponty is the phantom limb. A phantom limb is the sensation, which may be painful, emanating from a body part (usually a limb) that has been amputated. The phantom limb feels painful or itchy, but the real limb has been removed, sometimes a long time ago. This phenomenon has been a riddle to physicians for centuries. How can a limb that is no longer there cause any sensation at all? What exactly is hurting when the phantom limb hurts? This baffling phenomenon could not be accounted for by a physical naturalistic explanation, because the nerve endings that seem to be sending pain signals to the person's brain are simply not there. How can you experience pain or tickling in a hand that was amputated years ago?

If we return to Merleau-Ponty's distinction between the biological and the lived body, we can explain the phantom limb as a rift between the biological body and the lived experience of it. The biological body has no limb, but the lived body feels that limb as

present, painful, itching. It is no use telling the person that their limb is not there, or denying their lived experience. The phantom limb is the expression of the body as it used to be, based on decades of having a body schema with four limbs. This habitual body is not destroyed instantaneously when the biological body loses a limb. The body schema must be reconstructed, new bodily habits and movements must be created, to compensate for the loss. And sometimes, as in phantom limb cases, the lost limb continues to exist, so to speak, in the lived experience of the person.

Another example of the rift between the biological and the lived body is anorexia nervosa. If we look objectively at the biological body, we may see a skeletal, emaciated body. This is the biological body, whose thinness can be measured by weighing it or calculating its body mass index. But if we ask the anorexic to describe her body, she may say that she experiences it as obese, cumbersome, large. The subjective body, or the body as lived, is a fat, monstrously corpulent body. As we know, denying this experience by making an appeal to the objective facts is unhelpful. Here, again, we can see the rift between the body as it is objectively and the body as it is experienced.

Understanding this rift gives us the tools to describe the impact of illness. Because the body under Merleau-Ponty's description has a much more central role, and because illness changes the body, the impact of illness is more significant than we may have previously thought. We can now begin to see how being ill is not just an objective constraint imposed on a biological body part, but a systematic shift in the way the body experiences, reacts and performs tasks as a whole. The change in illness is not local but global, not external but strikes at the heart of subjectivity. Because "I do not bring together one by one the parts of my body; this translation and this unification are performed once and for all within me; they are my body itself ... I am not in front of my body, I am in it, or rather *I am it*" (Merleau-Ponty 1962: 150, emphasis added).

My ill body

We are creatures of habit. I have already forgotten what it was like before. Before I was ill. Before I lived in the shadow of chronic breathlessness, fear of infection, and the endless need to take care of things. The endless need to arrange oxygen deliveries, attend scans, renew my prescription, pick up drugs, take drugs, attend consultations – in short, the need to manage my illness.

My illness has become part of my life at an incredible pace. At first it was an external disaster; something that wasn't meant to happen to me; something extraordinary, while I was ordinary. In the first week after my diagnosis I would wake up, blissfully ignorant of the new reality of my life. After a moment, as I awoke, the realization that something had gone horribly wrong would crash down on my sleepy head. These moments of being awake but not remembering I was ill quickly disappeared. A new era began. My illness was internalized and became part of my life, part of me, my body.

My body adapted with astonishing alacrity to new limitations. My mind quickly forgot how things were before. Within a year my physical habits were entirely different. Whereas in the first months my body would attempt a brisk pace, hurrying up stairs, physical impatience, these movements have been erased from my bodily repertoire. While my memory still contained images of mountain views and the inside of a gym, I could no longer remember what it *felt like* to run, to work out, the euphoric sensation of healthy exertion, the effortlessness of being young and healthy. New habits were formed and a new way of negotiating the world was incorporated into my physicality. Blissful forgetfulness of the pleasures of physical movement accompanied them.

In my pre-illness days I made plans and wanted the usual goods life offers us. I thought my wishes were mediocre, underpinned by a modest, implicit list of expectations: to be healthy, to be happy, to be safe. After I became ill, these wishes began to seem grandiose

and exuberant; the expectations seemed foolhardy, extravagant. Did I really expect all that? Did I really think that this list of infinitely complex, luck-dependent elements would just come true as a matter of course?

I began to think that I was asking for too much, that we all routinely ask for too much. That nothing could go smoothly all the time, let alone everything all the time. But I had another card up my sleeve. I was good. I ate a healthy diet. I exercised. I didn't smoke or drink. I took care of myself. When I compared myself with friends, many of whom have been heavy smokers for over twenty years, I felt I deserved to have the lives they have, just by chance, more than they do. I fell into the beginner's trap of suffering and asked: why did this happen to me? This question had no answer, or at least no answer we know of with current medical knowledge. It was an arbitrary stroke of very bad luck.

My expectations had to change, and change fast. My wish list narrowed down to having one item only: I want to live. I don't expect the shadow ever to lift from my life and disappear. I don't expect to have a family, to be able to pack up and go on a trip, to celebrate my sixtieth birthday or to spontaneously book a cheap flight to Greece. I don't expect to feel better. My only wish is to hang on to what I have now: being alive, having a moderate quality of life, doing some of the things I love. That's plenty, I tell myself. And it is this veneer of normality, this slightly sad and inappropriate sense of luck, that sustains me in my illness.

It is when I encounter pity, when people show some of their incredible sadness and anxiety for me, when people respond with shock and horror to my condition, that my story crumbles. And then I know: things work out for most people most of the time. Only 120 women in the UK and a few thousand worldwide have been diagnosed with LAM. It is true that other people have different problems. But if I look at my friends and acquaintances, most of them are entirely healthy. Most of them did go on to have healthy

babies. Most of them have all the things that were on my all too human wish list, but take them for granted. Most of them live in hubris of which they are blissfully ignorant. Instead, they have the naive, unreflective sense of desert. Why shouldn't things work out for me, they ask?

In the early days after my diagnosis I couldn't think at all. I didn't dare read about my illness or learn anything about it. I felt that any more information would only bring with it bad news, more horror, additional grim facts to petrify me. I suffered from what Joan Didion calls "magical thinking": the irrational, self-blaming, mystic thought that is apparently common in situations of distress. I blamed myself for writing a book on death. I blamed myself for going to the doctor so late. I blamed myself for being arrogant and not budgeting for something like this from the beginning. I blamed myself for daring to have a wish list.

Later, as I adjusted to my situation, I felt increasingly angry. I spent several months asking: why did this happen to me? I felt sorry for myself. I cried for days, with grief for the family I will never have, for the short and crippled life available to me. When I walked through the park I would look at the young mothers playing happily with their children and a wave of envy would wash over me. You will never have this, I would tell myself over and over: the sense of security, the naive belief in the goodness of life, long lazy afternoons in the park, mundane concerns about redecorating and scraped knees.

It was only through long conversations with another woman with LAM that I stopped the vicious circle of envy, self-pity and despair. Grazyna, who has been ill for a long time and suffered markedly worse ill health than me, became a dear friend. I felt I could talk to her because she, too, had LAM and she, too, faced the same challenges as me. She saved me from myself by listening with great compassion but also by refusing to accept the destructive views I voiced about our condition. She told me to stop moaning,

stop making a fuss about trivial things and start appreciating what I still had. When I complained about being stared at on the street because of my oxygen cylinder, she told me to look away from myself. To stop thinking I am so interesting to others and, instead, enjoy the freedom the oxygen provided.

Her refusal to accept my self-pity worked. I realized I needed discipline. I needed discipline in my illness management and I needed emotional discipline. I needed to take the drugs and see the doctor and have the scans and do the breathings tests and order the oxygen and renew my prescriptions and sleep with the oxygen mask even though it caused my nose to bleed. I needed to walk as much as possible and go to yoga three times a week and eat a healthy diet and take the vitamin supplements and get a flu jab every autumn and patiently tolerate invasive tests and painful medical procedures. This was the easy part.

Developing emotional discipline was much harder. I needed to learn to say no to negative feelings. I needed to learn to go and sit in a cafe when writing at home became morbid. I needed to stop looking at other people's lives and making up stories about their happiness. I needed to open myself to the knowledge that other people suffer too, that there are other kinds of pain and sources of misery. I needed to recite, even by rote, all the good things in my life and to cultivate that oddly optimistic feeling I had deep down inside, that everything was going to be OK.

I needed to learn to stop caring about what other people have. To focus on good things and look away from suffering. To avoid sad films and novels. To stop noticing children in the park. I had to kill a part of me to achieve that, but the trade-off was essential. I had to stop caring about people's stares and sometimes rude comments and learn to be rude back. I had to develop blindness to certain kinds of looks, and deafness to certain kinds of overtures. I had to learn to stop being nice at my own expense. I had to learn to say "I am disabled" when booking hotel rooms. I had to force myself to walk into a room full

of people with my oxygen on and my head held high, watch people's eyes widen with surprise and then look away, embarrassed.

I needed to immerse myself in new projects. And so we bought a house and adopted a rescued lurcher, Laika, named after the Soviet dog sent to space in 1957. I spent a long time training and walking her and my fitness duly improved. At first, the snail's pace crawl up the hill to our local park was utterly painful. But as time passed, I became a little fitter, or a little less conscious of how slow I was, and the walks became truly pleasurable. I discovered I enjoyed gardening and spent many afternoons in the sun, bending and lifting, watering and snipping away happily, at my limited pace. I went on walks, and cycled on my electric bike, the most ingenious gift I have ever received. And sometimes if it weren't for the baffled stares, I would almost forget anything was amiss. Things became abnormally normal.

The process of normalization is a curious one. It made me admire my body in its automatic, tacit wisdom. I learned what complex processes of compensation take place when lung tissue is impaired. How the body automatically increases the number of oxygen-binding red blood cells. How the heart works harder, pumping the blood ever faster through the lungs in an attempt to absorb more oxygen from a reduced surface area.

I began to self-censor actions and movements that caused me breathlessness. Every time I tried – and failed – to do something that was too strenuous, my body stoically registered the failure and thereafter avoided that action. The change was subtle, because this happened by stealth. The miraculous result created by my body's adaptive abilities was that I stopped feeling all the things I could not do. They were quietly removed from my bodily repertoire, in a way so subtle I hardly noticed it. The creeping changes added up, of course, but their impact was limited by the constant adjustments occurring at a subliminal level.

My habits changed. I began to plan each trip upstairs, compiling a small list in my head to avoid unnecessary journeys up one flight

of stairs, a journey that would leave me gasping for air, leaning over the banister panting for several minutes. I planned meeting places with friends according to gradient. Some parts of town or of buildings became off-limits to me: the top of Nine Tree Hill, my colleague's office on the fourth floor, top-floor flats. I began to feel amazed at people walking uphill while chatting on their phones.

My daily walk with Laika was planned meticulously to avoid unnecessary ascents. After being late to dozens of appointments I began to add fifteen minutes to my journey time. I began to arrive early at train stations and wait at the top of the stairs until the very last minute, in case of a platform alteration that would force me to climb up the stairs again. For many months I resisted the lift. I would walk up stairs slowly, excruciatingly breathless; people would often stop to ask whether I was OK. The day came when I gave up stairs and stopped trying to pretend I was the same as before.

I adjusted my walking pace to a slow, measured one. Whenever walking, part of my mind is now preoccupied with my breathing: do I need to slow down? Do I need to adjust the oxygen level? Should I try this hill? My days are now divided into "good days" and "bad days". Good days are exhilarating, elating. On a good day I can walk briskly (with oxygen) on the flat, walk up Old Ashley Hill at a very slow pace, get upstairs with only one stop on the way, hold yoga poses as long as the rest of the class. Bad days feel like death. On bad days my body closes in on me, reminding me constantly of my inability to do so many things. On a bad day, a trip down one flight of stairs to buy a cup of coffee is too much.

I remember still trying to do things. I remember a game of American football in Australia, on the lawns of the Australian National University, where I used to teach. My nimble friend Karen, who I was guarding, dashed ahead. I gave chase, but before I knew it she scored a touchdown. I remember playing basketball with friends and having to stop to rest every few minutes. I remember trying to run on the treadmill at the gym and having to stop. I remember

climbing out of a valley in the Blue Mountains in Australia and being left far behind by the others. All this time I thought I was weak-willed, lazy. I thought I needed to try harder.

Eventually, my body learned to stop trying. It learned to give up its habits and form new ones. I was told about the dangers of secondary pulmonary hypertension, damaging the heart, which is working so hard to pump blood into the lungs. I was told about the danger of a collapsed lung and respiratory failure. When I sleep alone I take the phone upstairs with me. Just in case.

My body has adjusted, its habits now largely transformed by its newly acquired limitations. But my mind still aches in its desire for freedom, for joyful movement, for physical abandon. I often dream about running. I am shooting ahead, running at an incredible pace, my feet hardly touching the ground. I run and run, unlimited by my breathing, exhilarated by my self-generated speed. It is these dreams that remind me of what has been taken away from me: the bodily freedom I hardly ever thought about when it was mine.

2. The social world of illness

Empathy. If I had to pick the human emotion in greatest shortage, it would be empathy. And this is nowhere more evident than in illness. The pain, disability and fear are exacerbated by the apathy and disgust with which you are sometimes confronted when you are ill. There are many terrible things about illness; the lack of empathy hurts the most.

I am in the respiratory department for my breathing tests. I begin preparing several days before the test. I always brace myself for a decline, telling myself: *you know* it will be worse this time. A further deterioration brings with it a further shrinking of my world, fewer things I am able to do easily, or do at all. Every month, as my breathing deteriorates, I wonder what will go next. Will I have to give up my electric bike? Will we have to install a downstairs toilet? Will I be able to continue practising yoga? Seeing your capacities diminish, your world becoming smaller and harder to negotiate, is never easy. Most people experience decline over decades. But seeing your abilities shrink at a terrifying pace at the age of thirty-five is horrific. Nonetheless, I know I must have the breathing tests.

A lovely nurse, Simone, is usually there, chatting to me, telling me about her boyfriend. But this time she is not there. Another nurse, sullen and unfriendly, leads me to the test room. She sets up the machine without saying a word, hands me a tube and tells me to blow into it as hard and as fast as I can. I take a big breath. I exhale into the tube. I blow hard. My face goes red, my body tenses, my shoulders quiver with the effort. I want good results. I want the