

The Vagabond's Breakfast

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For Rose, Sioned and Rhiannon Gwyn.

And for Lluís Peñaranda (1947–2010)
in memory of our friendship.

Je est un autre
(I is someone else)
Arthur Rimbaud

Now the rainman gave me two cures
Then he said, 'Jump right in'
The one was Texas medicine
The other was just railroad gin
An' like a fool I mixed them
An' it strangled up my mind
An' now people just get uglier
An' I have no sense of time
Bob Dylan

Yesterday evening, on entering my study, I saw the shadow of a
stranger escaping through the window. I tried to pursue him,
but I found no trace of him. Often I seem to hear people
hidden in the bushes around the house, especially at night.
Italo Calvino

1

Many years ago, it was Boxing Day – that much I remember – I was walking along an empty Mediterranean beach. The dull, overcast morning complemented my hangover. My life was a mess. In spite of an education and no lack of opportunities, I had become an aimless wanderer: a vagabond, a drunk, and occasional agricultural labourer.

I paddled barefoot through the shallow water, up and down, clutching my shoes. Small waves broke and spilled onto the shore, lapped at my feet. Because I was not looking where I was going I would have walked straight into it, but the stench made me stop in my tracks. A pair of gulls shuffled away angrily and flew off.

At first I could not make it out. It was a great grey mess of something, encased by a dark rim, abuzz with bluebottles. A brown carapace enclosed the chaos within, which was squirming with maggot life, slithering shapes burrowing and feeding in the remnants of purple and yellow flesh. When I realised that it was a giant turtle my revulsion gave way to the kind of melancholy that could only be induced by the sight of a dead and stranded creature eaten up by worms and grubs and gulls on a deserted beach. There was nothing to do but stare at it.

My friend Peter died that Boxing Day. He died a drunkard's death, a beggar on the streets of Athens. It may be a coincidence, but the poet and bouzouki player, Hubert Tsarko, another close friend of Peter's and of mine, told me that on the same day he had encountered the corpse of a sheep, rotting on the roadside outside the house where he was staying in the French Pyrenees. This replication of dead animals did not surprise me: things often seem to happen this way, as though there were a bizarre reflective symmetry at work in the universe, to which we commonly remain oblivious, but which manifests itself nonetheless, a fragile and tenuous architecture, superimposed on the structures of an oblivious world.

2

Hepatic encephalopathy is caused by the effect on the brain of toxic substances which have accumulated in the blood as a result of liver failure. [It] may cause impaired consciousness, memory loss, personality changes, tremors, seizures, stupor and coma.

BMA Complete Family Health Encyclopaedia

April 2007

My liver has been invaded by a virus. Last December, I was given a year to live, unless a suitable donor is found. Even if I receive a transplant, there are significant dangers: the new liver will not cure me of the viral hepatitis from which I suffer, but will in turn become infected. However, a transplant will, in the language of lifespan economics, buy me time.

Along with the diseased liver, I have a creeping madness, gases that gather in my gut and infiltrate the brain. I call it brain fog, but the doctors use another term: *hepatic encephalopathy*. One of the ironies of the condition is that it is almost impossible to say it whilst suffering from it. I wander around the house at night, unable to sleep, speaking to people who are not here. I have a tendency to conjure accomplices from the darkness. And I forget things that are supposed to have happened, while remembering things that probably did not.

One night, I climb to the loft of the house, where my study is located, in search of a cigarette lighter. When I step into the room, swaying under the dual onslaught of sleep deprivation and brain fog, I am on a mission. I have a cheap lighter in my hand, but it will not suffice, since according to the demented logic of some fleeting obsession, the lighter I am searching for has to be white, and the one in my hand is blue, an aberration. I spot the power lead that connects my laptop to the mains, and it terminates in a rectangular white fixture, which I remove, thinking it might also function as a lighter, and I attempt to light it with the blue one, convinced that the only way to ignite a lighter is with another lighter. I can smell burning plastic, but because of the defect in my cognitive wiring am not immediately

able to connect the smell with my own activity, until I realise that the melting fixture is burning my fingers. I am, at that moment, aware of myself as an alien presence, an utter anomaly, a man standing alone in his study having attempted, unsuccessfully, to set fire to a computer, or – which is the same thing – to his memory. The next day I find the blackened remains of the fixture hanging from my desk.

On another occasion, Rhiannon, my fourteen-year-old daughter, discovers me downstairs in the living-room trying to stuff a large blue alarm clock with bread. I stand there, in an agony of concentration, wedging a doughy ball into the mechanism with my thumb. I am muttering: *This happens all the time*. At least, this is what my daughter tells me: I have no memory of the event.

I search in vain for any purpose or symbolism behind these temporary losses of reason, or even of basic orientation. Besides, there is little opportunity for reflection of this kind. One evening, Rose, my wife, finds me walking in circles around the bedroom, and I will not respond to any questions from her other than by raising one arm and saying ‘No’ in a loud voice, flapping one arm like an acolyte of Mussolini, and going off into sudden quieter monologues, barely audible at times, and not consistently in English, but drifting off, on occasion, into other languages, both familiar and invented. Eventually I calm down, but early the next morning Rose cannot wake me from sleep, and has to call emergency services to take me to hospital. I do not recognise her or anybody else, and am in a state of semi-consciousness, which declines, alarmingly for Rose, into semi-coma. I remember nothing at all about that night or the following day. In the intensive care unit, a doctor tells Rose that I might not pull through, that it is touch and go. I later discover that only one in five patients survives a coma brought on by encephalopathy.

Before I am fully unconscious, six paramedics and male nurses try to sedate me, and I fight them off with flailing limbs. Rose intercedes, trying to calm me, mutters soothing words, since the efforts of the paramedics are not successful, but she cannot restrain me, my body is out of control and not responding to any instructions. One of the nursing staff thinks I am drunk; Rose informs her pointedly that I haven’t drunk alcohol for many years.

But, despite my abstinence, viral hepatitis is destroying my liver, reducing that organ to end-state cirrhosis. As one reliable medical website puts it: “Liver cirrhosis in the advanced state is characterized by protein wasting, as indicated by the loss of muscle mass, hypoalbuminemia, and an abnormal amino acid profile. The protein wasting condition cirrhosis is associated with a poor prognosis and reduced survival.” Once you’ve reached this stage, the chips are in.

Cirrhosis of the liver, duodenal ulcers, perforated oesophagus, thrombocytopenia, umbilical and inguinal hernias, ruptured varices: the prognosis is poor, and the failure of my liver to process proteins causes ammonia to seep to the brain, making me temporarily insane. I can write this in a moment of lucidity, fully aware that another attack is most likely imminent. I might have one now, as I sit writing at my desk, though the chances of this are reduced, apparently, by limiting my intake of protein, while consuming a lot of carbohydrates. They have also given me some medicine to help with the encephalopathy, which makes a person shit at least three times a day, often more. It accelerates the digestive and excretory process. In this way, the toxins passing through the liver have less time to transform into ammonia and cloud the brain. I avoid madness by shitting more. It amuses me, the way that the wellbeing of brain and bowels are so movingly interconnected. Get the crap out before it gets to the brain.

Like many sick people, I engage in a form of denial about the state of my health. However, this denial is facilitated by the remarkable sense of wellbeing, of catharsis even, that I enjoy on release from this last frightening episode in hospital, following my collapse.

I am in the bathroom at home the next morning when I experience what can only be described as a sort of epiphany. Starting as a trickle, my mind gradually becomes flooded with a delirious outpouring of ideas, bustling with each other for an outlet, and the clarity of my thought, in contrast to the confused and foggy torpor of preceding weeks, has the impact of a revelation. As I stand under the shower of warm water, the spring sunshine flooding through the bathroom window, I am overtaken by a physical premonition of wellbeing, of good health and energy, and I become convinced that the *power of the imagination* will guide me through the process of healing, and that the means to

achieve this will be through my work, through the poems and stories I write. With that realisation comes, in rapid succession, a summary list of tasks: articles, projects, entire books, which until then have managed only the vaguest delineation, assume a bewildering clarity and, in the fashion of a sculptor who has been staring at a block of marble for an intolerable age, and who then sees, down to the finest detail, the figure that lies hidden within the stone, I know exactly what I have to do. I sort these embryonic works in my mind, and pursue each one in turn for a while – each cocooned in the potential of its eventual completion – and with a joyous certainty bubbling inside my brain, I step out of the shower, dry myself, and rush up to my study, noting down all the ideas that have occurred to me in the bathroom.

It is as if all this energy, all this creative power, has lain dormant, suppressed by inertia during the last few months, in which I have been incapable of writing anything, of even thinking coherently; and it is my *illness itself* that has plunged me deep into that dark, secret, unconscious place where, paradoxically, new ideas are born. I have surfaced from the dark and hollow pit and, with the bathroom luminous with sunlight and the water rushing over me, everything seems to slot sublimely into place.

It is much later that night, riveted to the white noise of the TV, that I reflect on what has happened, and realise there is something deeply suspect about this degree of euphoria.

3

Liver cirrhosis is known to be incurable, and even though a person might live with mild cirrhosis for many years, once a patient such as myself has entered what is comfortingly known as ‘end stage’ cirrhosis, there is no remedy other than liver transplantation, or death (itself a remedy of sorts). Until quite recently, the notion of being healed of cirrhosis would have been unimaginable; and even now, in order for me to survive, someone else – a stranger – has to die. In spite of the advances being made in the development of indigenous cell cultures, which should result, eventually, in people being able to grow their own replacement organs, the telephone will only ring to summon me to hospital because someone who has pledged their liver to medical science has passed away, or even more disturbingly, is about to; and that incites a very confused range of emotions.

In the cold hours before dawn, as I sit at the keyboard, disoriented and insane with sleeplessness, I rather doubt that the transplant will ever happen. I will either have to wait so long for the right organ that my body will be too weak to undergo the arduous operation, or else I will suffer another, terminal episode of encephalopathy. It is not surprising that I succumb to these doubts, but I do resist them.

And then there is the thorny issue of my moral entitlement to a transplant. Much has been written on this theme, and with the rising demand for organs, and the failure of government in getting people to make ‘lifestyle choices’ that stop them from wrecking their livers, such debates are likely to continue. But, unlike other hepatitis C patients with whom I have spoken, I have not suffered discrimination based on moral censure. It has been decided, following the criteria by which these judgements are made, that I am a worthy candidate for transplant. I cannot argue with that, though others may.

I have no idea when I acquired the virus that is killing me, though at times I cannot help but reflect on what ultimately caused this state of affairs, this breakdown of the body and the senses. Remarkably, my illness has nothing to do with the damage done to my liver by alcoholism. I was able to recover from that addiction many years

ago, and under normal circumstances the liver, whose powers of recuperation are astounding, would have regenerated of its own accord. But I need to retrace my way through two decades of reckless living; not in order to track the precise moment when I carelessly contracted hep C – there are several candidate dates, spread over a few years of sporadic intravenous drug use in my early twenties, along with a couple of suspect blood transfusions – but in order to try and make sense of the *present*. I need to try and hold the present in place – because it is so fragile – by propping it up with what I can remember of the past. By recounting the story, or fragments of the story, perhaps I can achieve a better understanding of what this illness is telling me, even if that account is dislocated, fails to cohere, and lacks resolution. It seems to me that the course of one's life is determined by serendipitous meetings and improbable acts of entropy, rather than by expecting, or willing some coherent pattern to emerge, one by which we can plot our track like doomed explorers.

Most people who are ill wish to imagine the story of their illness as one of *restitution*, in which health is regarded as the normal condition to which they will be restored. According to the medical sociologist Arthur Frank the basic plot of their narrative goes something like this: “Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again.” The restitution narrative is the one that other people want to hear and which provides the medical care system with its *raison d'être*. Counteracting this is the *chaos* narrative, which contravenes the principles of restitution. Its plot imagines no return to wellness. Chaotic stories reflect the chaotic trajectory of the illness, lacking causality or sense. Chaos negates the expectation that in life one event leads to another: for this reason, chaos stories are unbearable. But even narratives of restitution contain within them, or are subject to diversion by, hostile or chaotic forces. Sometimes the course of an illness *does* descend into a state of chaos, and from this perspective restitution seems a distant dream. My illness experience has exposed me to both narratives, but neither of them is sufficient in itself.

Susan Sontag has written that illness is another country, a kind of parallel existence with its own laws and language: “Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds

dual citizenship, in the kingdom of the well and in the kingdom of the sick.” When we are ill we learn to speak the language of illness, and not only by describing it, by learning its terms and conditions, its secret passwords. We might think we know our disease and through our knowledge gain some degree of power over it. The way we do this is through our narratives, through the stories we tell, in which we attempt to contain and direct the course of our disease. But I have found, of late, that the disease keeps intruding on my narrative, like an over-protective author, ridiculing my attempts to corral it into a story of quest or of restitution. I find its presence in the notebooks I inscribe by hand at night, the illegible scrawl, the spider trail of ink on the page as I stumble through words as if bereft, confined to an inferior idiom, a sort of mumbling litany, a language of decrement and insanity. I have learned the vocabulary and syntax of the disease which is in my blood, but it has now spawned this new complication, the encephalopathy that seeps into the brain, causing confusion and a vague sense of regret.