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Never Mind

*There is no such thing as balanced indifference. There is no center or axis; it cannot be found, or is absent.*¹

Violet is unbalanced.

A series of strokes, left-sided hemiplegia and a growing cancerous breast tumour have left her noticeably lopsided. At times when we talked the old woman would slip away from me, her eyes drifting off somewhere to what lay beyond the top of my left ear. Our first interview felt like a disaster. With the coming and going of her attention I rushed into the silences and pauses with stupid, unnecessary questions, my way of trying to restore some tempo and convention to the interview. She did not seem to hold my foolishness and anxiety against me. When we next met in her home, I was greeted with some affection ‘There’s my friend Yasmin!’

Over the three months that I got to know Violet, she trained me to say nothing during her absences. I learned to wait for her to return and in the waiting to pick up on my own leanings.

‘How can the right-handed person be described?’ the left-handed philosopher Michel Serres has asked, offering,

As a severed organism . . . Hot and supple, one side of the body and its extension lives, trailing behind it a sort of cadaverous twin, stiff and cold, contemptible and impotent – in short, unconscious.²

Serres’ point is that we are all inclined and out of kilter, dragging behind us a neglected forsaken side. Serres’ sense of sensibility is that it operates as a

fluctuating, directional pull, a tugging of the eyes, mouth, ears, nose and skin that is helplessly open and skittish.

The conjoined twins of disability and disease pull Violet in different directions. The left side of her body is leaden and icy, drooping downwards in a yogic hyper-relaxation. Her upper-right-side skewered by the tumour, lists feverishly away from the left in a new growing compulsion. Between these divided fidelities, any autonomy she has demands other forms of asymmetry. As a patient-in-residence, Violet is always dependent upon others. She can pour water from her jug only if it is half-filled and in close reach, at a certain height and angle on her bedside table. She makes constant, seemingly petty demands upon the nurses, micromanaging the positioning of bottles, tissues, newspapers, biscuits and fruit.

For some patients bedside tables are small recreations of home,³ transplanting elements of bedroom, kitchen and bathroom.⁴ A small brass tazza, hot pepper sauce or a bottle of Bay Rum can bring instant domesticity and comfort to an institutional space.

Violet's bedside table is her lifeline. It is a rope of plaited duties and favours tossed towards the right of her body, bringing cramped opportunities to potter and to feel about. In the economy of a restricted life-world trivia have an inflated value that can baffle and infuriate outsiders. For the nurses, Violet is a *difficult patient*, one of those people in the ward that they are reluctant to pull up a chair beside and to talk to when they have a few minutes to spare.

Violet resents her increasing dependence. 'I don't depend on my family or friends. I wasn't dat person before I took sick, so is very difficult for me. I jus don't like to give people trouble, bother no-one. I don't like it.' What Violet does lean on is her Pentecostal religion. It gives her suffering direction and purpose. It brings her closer to Jesus.

When she was diagnosed with breast cancer, Violet refused to have the tumour in her right breast operated on, choosing to be treated only with radiation and chemotherapy.

From de time I saw dis lump in my breast, I discover dat it would be something like cancer, so when dey tol me, it wasn't strange to me. I said 'Well if I go an dey tell me it's cancer, I'll accep it', which I did. What dey wanted was to hoperate an I said 'No. No. I don't want de hoperation. I don't want no hoperation on it'. I stan against dat very much. I'd rather die wit it dis way. I don't believe in hoperation. There are some times when dey hoperate on you an den you could live a few more days longer, but because of dat hoperation you can also go quicker. So dat's why I'm not keen on it.

Without surgery Violet's tumour has continued to grow, forcing itself through her skin into a malignant fungating breast lesion. Fungating is the medical term for an open rotting wound. Fungating wounds are painful, seeping and malodorous, a constant reminder of a progressing fecund disease. Fungating lesions lure senses to the interior of the body, to a secret world of carnal life and sensations devoid of referents in modern Western cultures. Among the Anlo-Ewe people of South-Eastern Ghana there is a basic perception verb *seselelame* that refers to both sense knowledge and to sensations. It is the sensing of sense. It can be used to connote the tingling of the skin, hearing, smell, sexual arousal, intuition, kinaesthetics and balance. *Seselelame* is translated as 'feel-feel-at-flesh-inside'.⁵

The lively density of Violet's tumour transported through *seselelame* gives her little respite. Every movement – to stand or to turn, to pick up a glass or to readjust the blanket over her knees – can strain and pull at her body's fraying edges. Sleeping is what she finds most difficult. There are few comfortable resting places, only *pain, pain, pain*.

As a cancer develops, it can explore outwards like a curious, awesome infant, an evanescent energy of mass, fluid, rhythms and pressures that is a distinct presence, even as it suckles from and merges with blood, muscle, bone and skin. The slow birthing of malign matter into the outside world through fluids and odours perforates what the French psychoanalyst Didier Anzieu has called the *skin ego*,⁶ a containing envelope of skin and psyche that marks off the self from others.

Every breath for Violet and those around her is an inhalation of decay and death.

Silver lining

The topical application of a sugar paste and honey, or dressings with charcoal or silver nitrate can control the growth of bacteria in a wound and absorb offensive smells, temporarily sealing off an effusive body. Returning it to the present, to visitors, to a home. A body that has been bound, quieted and made private is a body that is less menacing in Anglo cultures, even though all bodies leak.

Among hospice patients whose bodily surfaces could not be restored, the anthropologist Julia Lawton has observed that some patients began to retreat into an inert existing, even when they retained the capacity to communicate with others and to be mobile.⁷ They were moved around the hospice, often into single rooms. Other patients and relatives complained about the smell. As the putrid insides of a body flowed outwards, Lawton found that personhood could

withdraw in a psychic 'switching off'. Like strangers in the night, the outgoing body and the retreating self could pass each other by.

Those who care for Violet have noticed her lack of presence. They interpret it in different ways according to whether they are thinking about her stroke-induced impairments or other biographical coordinates. A hospice inpatient nurse writes 'Her concentration span is very short, ? dementia'. Violet's hospice home-care nurse, Janice, who has known Violet for some time, finds her stoical, one of her older patients who would never make a fuss about her symptoms. Janice shudders when she recalls seeing the dressings on Violet's breast lesion being changed by her district nurse.

You know it's hard to imagine that that wasn't a terribly painful procedure for her. She clearly was in pain. She would wince you know. And you felt that she was having a lot more pain than she would acknowledge really.

Whether she is helping with wound dressings, taking blood or listening to stories about the grandchildren, Janice maintains an acute openness to the rich textures of body and soul that rain in on her on a daily basis. A new smell, a change in posture, some play of hue in a complexion, an unusual dilation or constriction of the pupils, a snide exchange between family members are all taken in and registered. With each new symptom, surprise or misunderstanding her palette of care grows a little and becomes more dappled with each patient.

It is a form of body work somewhat akin to that found in the training of 'noses' in the perfume industry, where a novice must learn to identify the subtle chemical distinctions within and between odours: the nuances of amber, hay and tobacco in Clary Sage. The warmth of civet musk or the vanilla-almond of a heliotrope. The philosopher Bruno Latour has dubbed this unfolding of the world with the body as a lively process of *learning to be affected*. Once amateur noses have gone through a weeklong training session Latour observes how,

... the word 'violet' carries at last the fragrance of the violet and all of its chemical undertones ... words finally carry worlds. What we say, feel and act, is geared on differences registered in the world.⁸

And so it seems that by listening to Violet and her family, and by smelling, touching and observing, a world of tonal contrasts and accords also emerges in Janice's apprehension of her Violet. As always with auscultation there is uncertainty.

I think Violet's life was hugely compromised when she had her stroke, because of course she wasn't mobile, she wasn't independent and in many ways the breast cancer was almost an incidental because it wasn't actually incapacitating her

because she was already immobile. But I am only surmising and I suppose I felt that Violet was a lady who had been a victim in her life, and this is more on an emotional level, but you know we shouldn't just sort of cast that aside as not being important. I think she had always been a victim, and I think she remained a victim in a way. She was a vulnerable lady. She was disadvantaged in many ways. She wasn't particularly an articulate lady, and although she was demanding in some ways, she was also accepting in others. It was, you know, a bit of a mix there and she did seem to accept her disease on the surface with this sort of equanimity, but I don't think, you know, I think at times, although she seemed to be accepting, you know, at the end of the day who wants this dreadful thing, the thing that every day she was witness to? And yet she had refused treatment. You know, there was a strange mix there really, that I, I never, and I don't know whether anybody ever did, get to the bottom of really, because you know she had to have her dressing changed everyday, so that was a daily reminder that she had a nasty, horrid, painful lesion there.

This backstory of Violet had been prompted by a disclosure from Violet's daughter of the violence her mother had endured during her marriage. Frustrated at her own complicity with the pretence of a happy marriage, Janice nevertheless respected Violet's opacity 'I suppose one has to work with what you're able to'. And Janice did this work by managing Violet's dressings, pills, patches and creams and by risk-taking and stealth. She would encourage and gently coax Violet into saying more about herself. Hoping for a spark of something, knowing that it might never come.

On a home visit, Janice talked to Violet about a recent change in her pain control. She crouched down onto her haunches so that Violet did not have to look up to her. She lowered her voice for discretion 'Violet I can see that you haven't been taking your Oramorph tablets that the doctor gave you for the pain'. Without any signs of an emerging dialogue about Violet's refusal of the opioid analgesics, Janice moved into multiple-choice questions and possibilities 'Did you forget to take the tablets, Violet? Do you not like taking tablets? Would you prefer to take a liquid instead?' Each inquiry or suggestion was met with a blank stare or an *I don't know Dear*. But Janice kept going, searching gently for reasons and possibilities until Violet said that she was not taking the tablets because she did not want to become addicted to the drug. Janice was reassuring about the safety of prescribed morphine, but she knew that this standard script would not be enough. She persuaded Violet to try a synthetic analgesic, Fentanyl, absorbed into the body through a patch stuck to the skin. A small, but not insignificant result.

Yvonne, Violet's eldest daughter, appreciated Janice's insight and her perseverance. One day, after we had finished a home visit and were on the way to Janice's car, Yvonne came out after us. Standing on one of the many communal paths in the housing estate, Yvonne told us against grey skies that her parents are of a generation that is deferential to authority and to professionals. Violet is someone who would not find it easy to ask for more help and support 'You'd have to drag it out of her' Yvonne tells us.

For better or for worse, Violet is not entirely deferential. As Janice recognized, to go against medical advice – the weight of statistics and clinical trials, the case comparisons, the ticking clock and the poised pen – takes courage and strength. Non-compliant patients, who remove themselves from the conveyor belt that moves seamlessly from diagnosis to treatment, test the authority and moral fibre of medical and nursing staff. Treatment does much more than cure, exorcise or manage disease. It is the means by which medicine measures and validates itself.

In the contemporary ethos of *partnership working* and *the expert patient*, doctors must accept and honour a patient's decision. A referral letter from Violet's hospital is non-judgemental, to the point. 'Mrs Lawrence is firmly of the opinion that surgery spreads cancer and has therefore declined our interventions'. But there are striations of resentment and frustration among some of the professionals who care for Violet. A doctor 'I would imagine that she can present as socially pleasant, but in reality, I think she has little insight into how to look after herself'. Other members of Violet's inpatient hospice care team point to her indolent introversion, her excessive demands on their time and personnel. Because of her disabilities it takes two people to move Violet. She is what they describe as 'well-covered', making her heavy and cumbersome to assist. Violet can spend up to an hour on the commode trying to pass urine, a nurse half-complained, half-described to Janice.

Talking to Violet was hard work too. I found her laconic. Our conversations would often stall or be batted off-course with a perfunctory *I don't know* Dear or an out-of-the-blue chuckling. *I don't pay it no mind* was an apt, often used part of Violet's vocabulary, recurring when she talked about difficult situations. I heard it for the first time when she told me about her efforts to find a job as a new migrant to London in the 1960s. 'Well you know dey used to call us names', Violet said.

I mean you go for a job and ting and dey see you coming, then say 'We don't want any blackies . . . We haven't no job for no blackie. Go back to where you

come from, and ting like dat. When you go to work they skin up their face agains you. But we learned dat you know, we just pay dem no mind really, and we didn't pass back no word at dem, nor nothing, because being we weren't brought up dat way. And we have white people in the West Indies and we treat dem very good. We work with dem. We do everyting for dem. So it was strange for us coming here, an dey treat us like dis, like wasn't like at home. The white people in de West Indies were very nice. Nice people.

So how did you actually feel when you went for a job and they would say things like that ?

Jus don't pay it no mind, Dear. I just ignore everyting. We ignore everyting.

This observation of the strange behaviour of white people on their home turf compared to the *nice* white English people in Jamaica was still a puzzle to Violet and one in which *paying no mind* was the superior moral response. Jamaica Kincaid's memoir *A Small Place*, that records the colonial presence in Antigua, suggests that the English could be just as 'ill-mannered' in the Caribbean.⁹ An Antiguan response – very much like Violet's – displaced recognition of racism with a moral rhetoric 'We felt superior, for we were so much better behaved and we were full of grace. . .'.¹⁰

Such moments of lively story telling from Violet, of being curious and puzzled by life, were rare during our conversations. With Violet there was a sense of a withering of connections with others and what was outside herself. The external world was becoming more distant, receding and being nudged into the background.

As her disease advanced, Violet took to spending most of her day when she was at home, living in two square metres of space. Her confinement and domestication were not far removed from parts of my own daily life (when I am not teaching) and the dislodged reality of millions of cyber-addicts and workers in cities across the world, tethered to screens and simulacra in what the writer Paul Virilio has described as an uncanny 'spastic immobility'.¹¹ Although Violet's imposed captivation is without the sociality that cyber space can offer, it was somewhat softened by a circle of her most precious and utilitarian objects, including a bible, clock, television remote control, a pack of cards and an aerosol air freshener. The citrus-vanilla undertones of the air freshener would momentarily deodorize the fetid air in Violet's sitting room. Ultimately, the functional fragrance of the spray with its soapy tonality would be recruited into the animalic base notes of the cancer so that it became nauseating and oppressive.

Violet said that she chose not to have friends to visit her during this time. She said that she tired quickly. And she did not need to go to church because healing can take place anywhere. But visitors were also staying away, ashamed and fearful of being so directly assaulted by the stench of illness and death.

Theorizing the revulsion caused by such *dirty dying*, Julia Lawton suggests that over-spilling bodies pose a double threat. They terrify and threaten Anglo-European ideas about personhood as enclosed and privatized, and they undermine distinctions between order and dirt. Making sense of her observations of the lonely deaths of hospice patients who were avoided by other patients and their own families as their bodies unravelled, Lawton writes

The smells, and other fluids and matter emitted from the unbounded body, extended the boundaries of the patient's corporeality, such that the patient's body 'seeped' into the boundaries and spaces of other persons and other places. . . . In effect the other participants in the hospice were trying to maintain the integrity of their own selves, by avoiding having their bodily boundaries breached by the corrosive effects of the sick person's bodily disintegration.¹²

'What does cancer smell like?' is a recurrent topic in the blogosphere, with patients and carers exchanging their experiences and suspicions about the meanings of cancerous scents, likened to vinegar, Swiss cheese, stale sex, mushrooms or sweets. One woman noticed a smell around her that was most pronounced when she used the toilet. A man picked up a scent near his partner's left breast, that he recalled from his mother's breast cancer, 20 years earlier. Another could smell a sour-wine odour on her husband that lingered in the bedroom and on the sheets. He was subsequently diagnosed with inoperable colorectal cancer. Most of these people seek reassurance that they are not mad to trust in the contact they have made with the body's aromatic ghosts; a contact and participation in an olfactory world that is also made by dogs and is being used to develop electronic noses that are able to distinguish between healthy and malignant breath.¹³ The leap outside of reason brings these courageous apprentices in the art of *seselelame* full circle to a rendezvous with cutting-edge medicine and to an intimate attunement with human vulnerability that clinicians have mostly forgotten. Or at least have tried to forget.

To smell is to feel and also to remember. Scent receptors at the back of the nose are connected to the limbic system, the most primitive part of the brain that is responsible for the processing of emotions and memories.

Les Fleurs du Mal

With the smell from her wound becoming more difficult to disguise and manage, Violet would only venture outside of her house for medical appointments or admissions. Even then, with the privilege of hospital or hospice transport, she had little direct contact with the streets. For this she was grateful. The pace of life in the London suburb where Violet lived had become too fast, too loud, too scary. On her last journey outside she felt wrong-footed and enfeebled by the shakiness of the ground underneath her. Recoiling from the world in infirmity is like learning to walk in reverse, a tottering regressive immobilization in which confidence, balance and bearings are slowly lost. The body tightens. Temperature soars and plummets. The jaw clenches, shoulders rise, the heart races, the gut churns. The world wobbles.

The pitching, rolling loneliness of an ever-increasing drift while all the time staying put is an inner migration. Yet Violet's solitary journey beneath the skin was more than the encumbrance of her disabilities, the lethargic heaviness of her movements, the tense asymmetries of an upper body curved around its open, stinky wound.

Frailty bends time and space. It had changed Violet's sense of her place in the world, of being in synchrony with herself and with others.

The nineteenth-century French poet and lover of all things urban, Charles Baudelaire, understood so well this metaphysics of infirmity. In the poem *Recueillement*, we find the poet wandering through the town at dusk with his *douleur* – his pain/sorrow.¹⁴ The anxious *douleur* is addressed and consoled as an indulged child, with the poet reframing and humanizing fearful nocturnal presences. Lost years are personified as old women looking out over their balconies. Regret is beneficent, emerging *smiling from the sea*. Restoring a fragile calm to all which threatens to overwhelm, the poem culminates with tender and wondrous expectation: *Listen, my Dearest, hear the sweet night march*.

I did not get the chance to say goodbye to Violet. I hold onto a fantasy that she had some sense of peace before her night came – that her *douleur* was comforted and reassured.

A month or so after my last visit to Violet's house, she was admitted into a nursing home for long-term care. Her husband was not able to cope with looking after her at home and Yvonne feared that Violet might once again become a victim of her father's violence. Less than a week after being admitted

into the nursing home Violet suffered a haemorrhage from her vagina. She was taken as an emergency to her local hospital where she was found to have a large undiagnosed pelvic mass. She died without regaining consciousness.

It is difficult to imagine that Violet could not *feel-feel-at-flesh-inside*. That she was somehow unaware of the weight of the gestating mass bearing down through her. It is more distressing to think that she was prepared to accept and endure quietly whatever fate bestowed upon her in a slow, passive suicide. Difficult probing questions were asked about the robustness of the protective membranes of care surrounding Violet. Plausible explanations were offered and interrogated. Without a post-mortem examination there was no evidence that the haemorrhage was cancer-related, Janice told me. Violet also had uterine fibroids that could have caused the bleed.

In the end the turbulent outpouring of Violet's life remained beyond Janice. She was utterly devastated by what happened and felt in some way responsible. She should have been more attentive, more pushy 'Violet wasn't always able to say what her problem was', Janice said. 'She really didn't make a fuss about the things that were causing her the most discomfort and that strangely was it seems, the cause of her death.' For anyone who cares, responsibility metastasizes, spreading to small crevices and tucked-away places that are not easily perceived or accessible. Techniques and protocols of care can be examined, evaluated and refined in the hope that future catastrophes can be avoided, but there is always an excess that cannot be put into words, that demands to be felt and to be remembered.

'Wild honey has the scent of freedom, dust of a ray of sun, a girl's mouth of a violet', wrote the poet Anna Akhmatova 'but we have found out forever, that blood smells only of blood.'¹⁵