

3 The Disembodied Lady

The aspects of things that are most important for us are hidden because of their simplicity and familiarity. (One is unable to notice something because it is always before one's eyes.) The real foundations of his enquiry do not strike a man at all.

—Wittgenstein

What Wittgenstein writes here, of epistemology, might apply to aspects of one's physiology and psychology—especially in regard to what Sherrington once called 'our secret sense, our sixth sense'—that continuous but unconscious sensory flow from the movable parts of our body (muscles, tendons, joints), by which their position and tone and motion are continually monitored and adjusted, but in a way which is hidden from us because it is automatic and unconscious.

Our other senses—the five senses—are open and obvious; but this—our hidden sense—had to be discovered, as it was, by Sherrington, in the 1890s. He named it 'proprioception', to distinguish it from 'exteroception' and 'interoception', and, additionally, because of its indispensability for our sense of *ourselves*; for it is only by courtesy of proprioception, so to speak, that we feel our bodies as proper to us, as our 'property', as our own. (Sherrington 1906, 1940.)

What is more important for us, at an elemental level, than the control, the owning and operation, of our own physical selves? And yet it is so automatic, so familiar, we never give it a thought.

Jonathan Miller produced a beautiful television series, *The Body in Question*, but the body, normally, is never in question: our bodies are beyond question, or perhaps beneath question—they are simply, unquestionably, there. This unquestionability of the body, its certainty, is, for Wittgenstein, the start and basis of all knowledge and certainty. Thus, in his last book (*On Certainty*), he opens by saying: 'If you do know that *here is one hand*, we'll grant you all the rest.' But then, in the same breath, on the same opening page: 'What we can ask is whether it can make sense to doubt it ...'; and, a little later, 'Can I doubt it? Grounds for *doubt* are lacking!'

Indeed, his book might be titled *On Doubt*, for it is marked by doubting, no less than affirming. Specifically, he wonders—and one in turn may wonder whether these thoughts were perhaps incited by his working with patients, in a hospital, in the war—he wonders whether there might be situations or conditions which take away the certainty of the body, which do give one grounds to doubt's one body, perhaps indeed to lose one's entire body in total doubt. This thought seems to haunt his last book like a nightmare.

Christina was a strapping young woman of twenty-seven, given to hockey and riding, self-assured, robust, in body and mind. She had two young children, and worked as a computer programmer at home. She was intelligent and cultivated, fond of the ballet, and of the Lakeland poets (but not, I would think, of Wittgenstein). She had an active, full life—had scarcely known a day's illness. Somewhat to her surprise, after an attack of abdominal pain, she was found to

have gallstones, and removal of the gallbladder was advised.

She was admitted to hospital three days before the operation date, and placed on an antibiotic for microbial prophylaxis. This was purely routine, a precaution, no complications of any sort being expected at all. Christina understood this, and being a sensible soul had no great anxieties.

The day before surgery Christina, not usually given to fancies or dreams, had a disturbing dream of peculiar intensity. She was swaying wildly, in her dream, very unsteady on her feet, could hardly feel the ground beneath her, could hardly feel anything in her hands, found them flailing to and fro, kept dropping whatever she picked up.

She was distressed by this dream. ('I never had one like it,' she said. 'I can't get it out of my mind.')

—so distressed that we requested an opinion from the psychiatrist. 'Pre-operative anxiety,' he said. 'Quite natural, we see it all the time.'

But later that day *the dream came true*. Christina did find herself very unsteady on her feet, with awkward flailing movements, and dropping things from her hands.

The psychiatrist was again called—he seemed vexed at the call, but also, momentarily, uncertain and bewildered. 'Anxiety hysteria,' he now snapped, in a dismissive tone. 'Typical conversion symptoms—you see them all the while.'

But the day of surgery Christina was still worse. Standing was impossible—unless she looked down at her feet. She could hold nothing in her hands, and they 'wandered'—unless she kept an eye on them. When she reached out for something, or tried to feed herself, her hands would miss, or overshoot wildly, as if some essential control or coordination was gone.

She could scarcely even sit up—her body 'gave way'. Her face was oddly expressionless and slack, her jaw fell open, even her vocal posture was gone.

'Something awful's happened,' she mouthed, in a ghostly flat voice. 'I can't feel my body. I feel weird—disembodied.'

This was an amazing thing to hear, confounded, confounding. 'Disembodied'—was she crazy? But what of her physical state then? The collapse of tone and muscle posture, from top to toe; the wandering of her hands, which she seemed unaware of; the flailing and overshooting, as if she were receiving no information from the periphery, as if the control loops for tone and movement had catastrophically broken down.

'It's a strange statement,' I said to the residents. 'It's almost impossible to imagine what might provoke such a statement.'

'But it's hysteria, Dr Sacks—didn't the psychiatrist say so?'

‘Yes, he did. But have you ever seen a hysteria like this? Think phenomenologically—take what you see as genuine phenomenon, in which her state-of-body and state-of-mind are not fictions, but a psychophysical whole. Could anything give such a picture of undermined body and mind?’

‘I’m not testing you,’ I added. ‘I’m as bewildered as you are. I’ve never seen or imagined anything quite like this before..’

I thought, and they thought, we thought together.

‘Could it be a biparietal syndrome?’ one of them asked.

‘It’s an “as if,”’ I answered: ‘*as if* the parietal lobes were not getting their usual sensory information. Let’s *do* some sensory testing—and test parietal lobe function, too.’

We did so, and a picture began to emerge. There seemed to be a very profound, almost total, proprioceptive deficit, going from the tips of her toes to her head—the parietal lobes were working, *but had nothing to work with*. Christina might have hysteria, but she had a great deal more, of a sort which none of us had ever seen or conceived before. We put in an emergency call now, not to the psychiatrist, but to the physical medicine specialist, the physiatrist.

He arrived promptly, responding to the urgency of the call. He opened his eyes very wide when he saw Christina, examined her swiftly and comprehensively, and then proceeded to electrical tests of nerve and muscle function. ‘This is quite extraordinary,’ he said. ‘I have never seen or read about anything like this before. She has lost all proprioception—you’re right—from top to toe. She has no muscle or tendon or joint sense whatever. There is slight loss of other sensory modalities—to light touch, temperature, and pain, and slight involvement of the motor fibers, too. But it is predominantly position-sense—proprioception—which has sustained such damage.’

‘What’s the cause?’ we asked.

‘You’re the neurologists. You find out.’

By afternoon, Christina was still worse. She lay motionless and toneless; even her breathing was shallow. Her situation was grave—we thought of a respirator—as well as strange.

The picture revealed by spinal tap was one of an acute polyneuritis, but a polyneuritis of a most exceptional type: not like Guillain-Barre syndrome, with its overwhelming motor involvement, but a purely (or almost purely) sensory neuritis, affecting the sensory roots of spinal and cranial nerves throughout the neuraxis. (*Such sensory polyneuropathies occur, but are rare. What was unique in Christina’s case, to the best of our knowledge at the time (this was in 1977), was the extraordinary selectivity displayed, so that proprioceptive fibers, and these only, bore the brunt of the damage. But see Serman (1979).*)

Operation was deferred; it would have been madness at this time. Much more pressing were the questions: ‘Will she survive? What can we do?’

‘What’s the verdict?’ Christina asked, with a faint voice and fainter smile, after we had checked her spinal fluid.

‘You’ve got this inflammation, this neuritis ...’ we began, and told her all we knew. When we forgot something, or hedged, her clear questions brought us back.

‘Will it get better?’ she demanded. We looked at each other, and at her: ‘We have no idea.’

The sense of the body, I told her, is given by three things: vision, balance organs (the vestibular system), and proprioception—which she’d lost. Normally all of these worked together. If one failed, (the others could compensate, or substitute—to a degree. In particular, I told of my patient Mr MacGregor, who, unable to employ his balance organs, used his eyes instead (see below, Chapter Seven). And of patients with neurosyphilis, *tabes dorsalis*, who had similar symptoms, but confined to the legs—and how they too had to compensate by use of their eyes (see ‘Positional Phantoms’ in Chapter Six). And how, if one asked such a patient to move his legs, he was apt to say: ‘Sure, Doc, as soon as I find them.’

Christina listened closely, with a sort of desperate attention.

‘What I must do then,’ she said slowly, ‘is use vision, use my eyes, in every situation where I used—what do you call it?—proprioception before. I’ve already noticed,’ she added, musingly, that I may “lose” my arms. I think they’re one place, and I find they’re another. This “proprioception” is like the eyes of the body, the way the body sees itself. And if it goes, as it’s gone with me, *it’s like the body’s blind*. My body can’t “see” itself if it’s lost its eyes, right? So I have to watch it—be its eyes. Right?’

‘Right,’ I said, ‘right. You could be a physiologist.’

‘I’ll *have* to be a sort of physiologist,’ she rejoined, ‘because my physiology has gone wrong, and may never *naturally* go right.’

It was as well that Christina showed such strength of mind, from the start, for, though the acute inflammation subsided, and her spinal fluid returned to normal, the damage it did to her proprioceptive fibers persisted—so that there was no neurological recovery a week, or a year, later. Indeed there has been none in the eight years that have now passed—though she has been able to lead a life, a sort of life, through accommodations and adjustments of every sort, emotional and moral no less than neurological.

That first week Christina did nothing, lay passively, scarcely ate. She was in a state of utter shock, horror and despair. What sort of a life would it be, if there was not natural recovery? What sort of a life, every move made by artifice? What sort of a life, above all, if she felt disembodied?

Then life reasserted itself, as it will, and Christina started to move. She could at first do nothing without using her eyes, and collapsed in a helpless heap the moment she closed them. She had, at first, to monitor herself by vision, looking carefully at each part of her body as it moved, using an almost painful conscientiousness and care. Her

movements, consciously monitored and regulated, were at first clumsy, artificial, in the highest degree. But then—and here both of us found ourselves most happily surprised, by the power of an ever-increasing, daily increasing, automatism—then her movements started to appear more delicately modulated, more graceful, more natural (though still wholly dependent on use of the eyes).

Increasingly now, week by week, the normal, unconscious feedback of proprioception was being replaced by an equally unconscious feedback by vision, by visual automatism and reflexes increasingly integrated and fluent. Was it possible, too, that something more fundamental was happening? That the brain's visual model of the body, or body-image—normally rather feeble (it is, of course, absent in the blind), and normally subsidiary to the proprioceptive body-model—was it possible that *this*, now the proprioceptive body model was lost, was gaining, by way of compensation or substitution, an enhanced, exceptional, extraordinary force? And to this might be added a compensatory enhancement of the vestibular body-model or body-image, too ... both to an extent which was more than we had expected or hoped for. (*Contrast the fascinating case described by the late Purdon Martin in The Basal Ganglia and Posture (1967), p. 32: 'This patient, in spite of years of physiotherapy and training, has never regained the ability to walk in any normal manner. His greatest difficulty is in starting to walk and in propelling himself forward ... He is also unable to rise from a chair. He cannot crawl or place himself in the allfours posture. When standing or walking he is entirely dependent on vision and falls down if he closes his eyes. At first he was unable to maintain his position on an ordinary chair when he closed his eyes, but he has gradually acquired the ability to do this.'*)

Whether or not there was increased use of vestibular feedback, there was certainly increased use of her ears—auditory feedback. Normally this is subsidiary, and rather unimportant in speaking—our speech remains normal if we are deaf from a head cold, and some of the congenitally deaf may be able to acquire virtually perfect speech. For the modulation of speech is normally proprioceptive, governed by inflowing impulses from all our vocal organs. Christina had lost this normal inflow, this afference, and lost her normal proprioceptive vocal tone and posture, and therefore had to use her ears, auditory feedback, instead.

Besides these new, compensatory forms of feedback, Christina also started to develop—it was deliberate and conscious in the first place, but gradually became unconscious and automatic—various forms of new and compensatory 'feed-forward' (in all this she was assisted by an immensely understanding and resourceful rehabilitative staff).

Thus at the time of her catastrophe, and for about a month afterwards, Christina remained as floppy as a ragdoll, unable even to sit up. But three months later, I was startled to see her sitting very finely—too finely, statuesquely, like a dancer in mid-pose. And soon I saw that her sitting was, indeed, a pose, consciously or automatically adopted and sustained, a sort of forced or willful or histrionic posture, to make up for the continuing lack of any

genuine, natural posture. Nature having failed, she took to 'artifice', but the artifice was suggested by nature, and soon became 'second nature'. Similarly with her voice—she had at first been almost mute.

This too was projected, as to an audience from a stage. It was a stagey, theatrical voice—not because of any histrionism, or perversion of motive, but because there was still no natural vocal posture. And with her face, too—this still tended to remain somewhat flat and expressionless (though her inner emotions were of full and normal intensity), due to lack of proprioceptive facial tone and posture, (*Purdon Martin, almost alone of contemporary neurologists, would often speak of facial and vocal 'posture', and their basis, finally, in proprioceptive integrity. He was greatly intrigued when I told him about Christina and showed him some films and tapes of her—many of the suggestions and formulations here are, in fact, his.*) unless she used an artificial enhancement of expression (as patients with aphasia may adopt exaggerated emphases and inflections).

But all these measures were, at best, partial. They made life possible—they did not make it normal. Christina learned to walk, to take public transport, to conduct the usual business of life—but only with the exercise of great vigilance, and strange ways of doing things—ways which might break down if her attention was diverted. Thus if she was eating while she was talking, or if her attention was elsewhere, she would grip the knife and fork with painful force—her nails and fingertips would go bloodless with pressure; but if there was any lessening of the painful pressure, she might nervelessly drop them straightaway—there was no in-between, no modulation, whatever.

Thus, although there was not a trace of neurological recovery (recovery from the anatomical damage to nerve fibers), there was, with the help of intensive and varied therapy—she remained in hospital, on the rehabilitation ward, for almost a year—a very considerable functional recovery, i.e., the ability to function using various substitutions and other such tricks. It became possible, finally, for Christina to leave hospital, go home, rejoin her children. She was able to return to her home-computer terminal, which she now learned to operate with extraordinary skill and efficiency, considering that everything had to be done by vision, not feel. She had learned to operate—but how did she feel? Had the substitutions dispersed the disembodied sense she first spoke of?

The answer is—not in the least. She continues to feel, with the continuing loss of proprioception, that her body is dead, not-real, not-hers—she cannot appropriate it to herself. She can find no words for this state, and can only use analogies derived from other senses: 'I feel my body is blind and deaf to itself ... it has no sense of itself—these are her own words. She has no words, no direct words, to describe this bereftness, this sensory darkness (or silence) akin to blindness or deafness. She has no words, and we lack words too. And society lacks words, and sympathy, for such states. The blind, at least, are treated with solicitude—we can imagine their state, and we treat them accordingly. But when Christina, painfully, clumsily, mounts a bus, she

receives nothing but uncomprehending and angry snarls: 'What's wrong with you, lady? Are you blind—or blind-drunk?' What can she answer—'I have no proprioception'? The lack of social support and sympathy is an additional trial: disabled, but with the nature of her disability not clear—she is not, after all, manifestly blind or paralyzed, manifestly anything—she tends to be treated as a phony or a fool. This is what happens to those with disorders of the hidden senses (it happens also to patients who have vestibular impairment, or who have been labyrinthectomised).

Christina is condemned to live in an indescribable, unimaginable realm—though 'non-realm', 'nothingness', might be better words for it. At times she breaks down—not in public, but with me: 'If only I could *feel!*' she cries. 'But I've forgotten what it's like ... I *was* normal, wasn't I? I *did* move like everyone else?'

'Yes, of course.'

'There's no "of course". I can't believe it. I want proof.'

I show her a home movie of herself with her children, taken just a few weeks before her polyneuritis.

'Yes, of course, that's me!' Christina smiles, and then cries: 'But I can't identify with that graceful girl any more! She's gone, I can't remember her, *I can't even imagine her*. It's like something's been scooped right out of me, right at the centre ... that's what they do with frogs, isn't it? They scoop out the centre, the spinal cord, they *pith* them ... That's what I am, *pithed*, like a frog ... Step up, come and see Chris, the first pithed human being. She's no proprioception, no sense of herself—disembodied Chris, the pithed girl!' She laughs wildly, with an edge of hysteria. I calm her—'Come now!'—while thinking, 'Is she right?'

For, in some sense, she *is* 'pithed', disembodied, a sort of wraith. She has lost, with her sense of proprioception, the fundamental, organic mooring of identity—at least of that corporeal identity, or 'body-ego', which Freud sees as the basis of self: 'The ego is first and foremost a body-ego.' Some such depersonalization or de-realization must always occur, when there are deep disturbances of body perception or body image. Weir Mitchell saw this, and incomparably described it, when he was working with amputees and nerve-damaged patients in the American Civil War—and in a famous, quasifictionalized account, but still the best, phenomenologically most accurate, account we have, said (through the mouth of his physician-patient, George Dedlow):

'I found to my horror that at times I was less conscious of myself, of my own existence, than used to be the case. This sensation was so novel that at first it quite bewildered me. I felt like asking someone constantly if I were really George Dedlow or not; but, well aware of how absurd I should seem after such a question, I refrained from speaking of my case, and strove more keenly to analyze my feelings. At times the conviction of my want of being myself was overwhelming and most painful. It was, as well as I can describe it, a deficiency in the egoistic sentiment of individuality.'

For Christina there is this general feeling—this 'deficiency in the egoistic sentiment of individuality'—which has become less with accommodation, with the passage of time. And there is this specific, organically based, feeling of disembodiedness, which remains as severe, and uncanny, as the day she first felt it. This is also felt, for example, by those who have high transections of the spinal cord—but they of course, are paralyzed; whereas Christina, though 'bodiless', is up and about.

There are brief, partial reprieves, when her skin is stimulated. She goes out when she can, she loves open cars, where she can feel the wind on her body and face (superficial sensation, light touch, is only slightly impaired). 'It's wonderful,' she says. 'I feel the wind on my arms and face, and then I know, faintly, I *have* arms and a face. It's not the real thing, but it's something—it lifts this horrible, dead veil for a while.'

But her situation is, and remains, a 'Wittgensteinian' one. She does not know 'Here is one hand'—her loss of proprioception, her de-afferentation, has deprived her of her existential, her epistemic, basis—and nothing she can do, or think, will alter this fact. She cannot be certain of her body—what would Wittgenstein have said, in her position?

In an extraordinary way, she has both succeeded and failed. She has succeeded in operating, but not in being. She has succeeded to an almost incredible extent in all the accommodations that will, courage, tenacity, independence and the plasticity of the senses and the nervous system will permit. She has faced, she faces, an unprecedented situation, has battled against unimaginable difficulties and odds, and has survived as an indomitable, impressive human being. She is one of those unsung heroes, or heroines, of neurological affliction.

But still and forever she remains defective and defeated. Not all the spirit and ingenuity in the world, not all the substitutions or compensations the nervous system allows, can alter in the least her continuing and absolute loss of proprioception—that vital sixth sense without which a body must remain unreal, unpossessed.

Poor Christina is 'pithed' in 1985 as she was eight years ago and will remain so for the rest of her life. Her life is unprecedented. She is, so far as I know, the first of her kind, the first 'disembodied' human being.

Postscript

Now Christina has company of a sort. I understand from Dr H.H. Schaumburg, who is the first to describe the syndrome, that large numbers of patients are turning up everywhere now with severe sensory neuropathies. The worst affected have body-image disturbances like Christina. Most of them are health faddists, or are on a megavitamin craze, and have been taking enormous quantities of vitamin B6 (pyridoxine). Thus there are now some hundreds of 'disembodied' men and women—though most, unlike Christina, can hope to get better as soon as they stop poisoning themselves with pyridoxine.