

The Disembodied Lady

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.

Our hidden sense, discovered by Sherrington. He named it 'proprioception'; 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.)

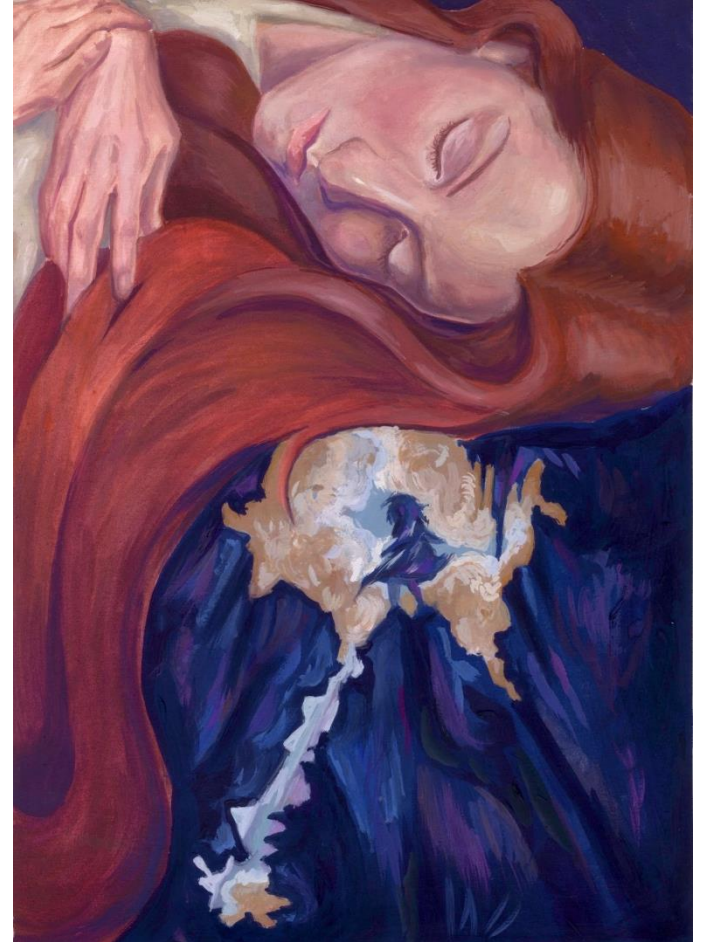
Christina was a strapping young woman of twenty-seven, given to hockey and riding, self-assured, robust, in body and mind. She had two young children and worked as a computer programmer at home.

She was intelligent and cultivated, fond of the ballet, and of the Lakeland poets. 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.')



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.

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

T*he 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.*

‘Yes, he did. But have you ever seen a hysteria like this?’

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.

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.

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.

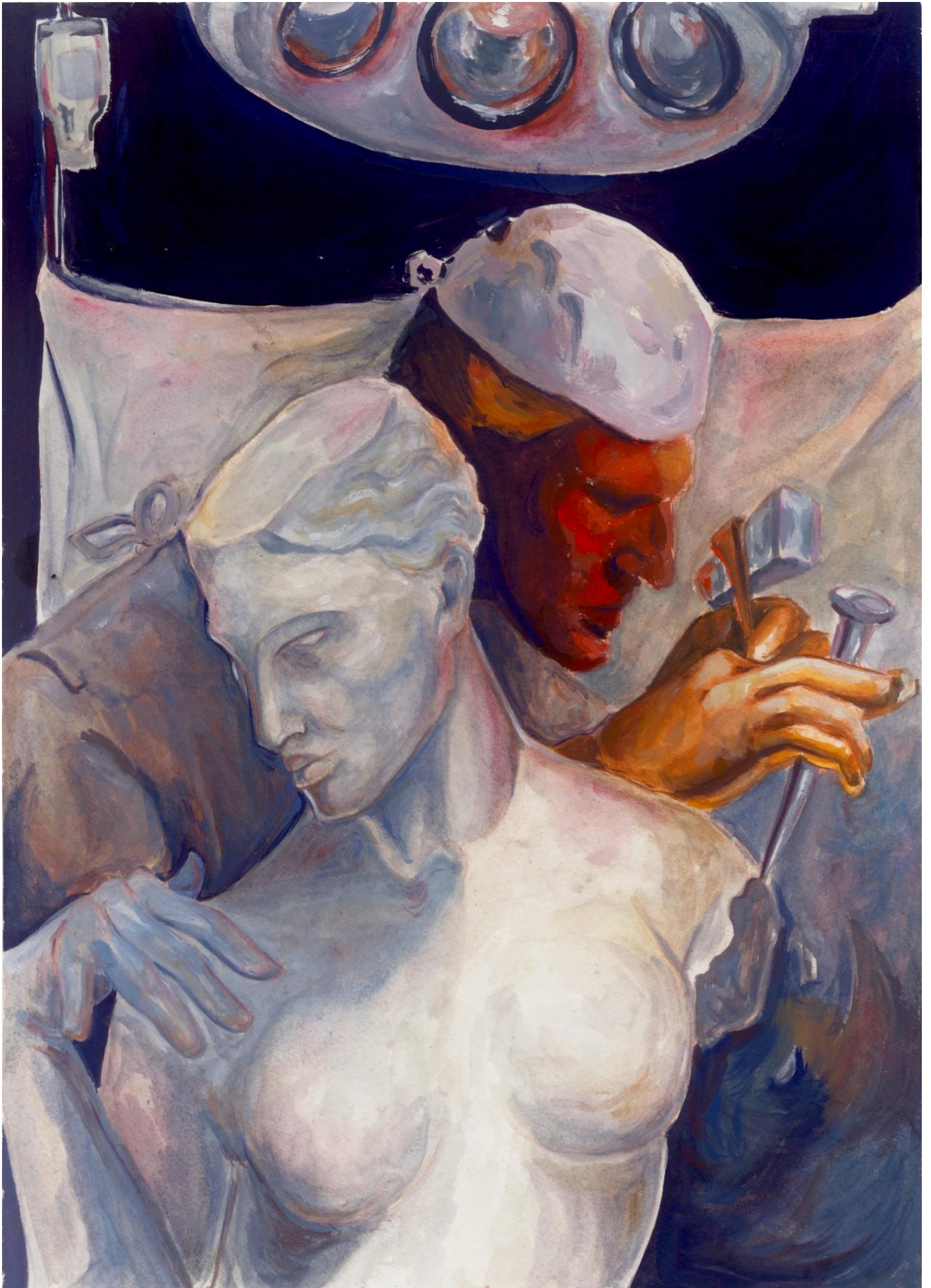
Operation was deferred; it would have been madness at this time. Much more pressing were the questions: ‘Will she survive? What can we do?’

‘What’s the verdict?’ Christina asked.

‘You’ve got this inflammation, this neuritis ...’

We began and told her all we knew. ‘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, and proprioception—which she’d lost. Normally all of these worked together. If



one failed, the others could compensate, or substitute.

'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?'



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 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 equally unconscious feedback by vision,

Christina learned to walk, to take public transport, to conduct the usual business of life—but only with the strange ways of doing things—ways which might break down if her attention was diverted.

by visual automatism and reflexes increasingly integrated and fluent.

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.

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.

Although there was not a trace of neurological recovery, there was, with the help of intensive and varied therapy. She remained in hospital, on the rehabilitation ward, for almost a year. 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.

'I feel my body is blind and deaf to itself ... it has no sense of itself'

She has no words, no direct words, to describe this sensory darkness 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'?

She tends to be treated as a phony or a fool. Christina is condemned to live in an indescribable, unimaginable realm. 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?'

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.