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## Twenty Years On

### **A Lost Beginning**

A little under twenty years ago, I was a research fellow trying to use a neurophysiological technique, spinal cord stimulation, for the relief of chronic pain in those with spinal cord injury. I spent lots of time with patients, during their visits to the hospital, in their homes, and even in pubs where we could sit and chat without the doctor/patient thing in the way. They would bemoan their pain and the poor treatment of it. Many had given up discussing pain with doctors, since conventional medicine had so little to offer. Some had tried aspirin, others morphine; a few found alcohol so useful they were concerned about addiction. Their proper doctors had little time to listen; some did not even accept their levels of pain.

My research project only showed the treatment to be ineffective in most pains. Indeed, in the end, and not before time, I realized that my project could never work, because for sound physiological principles it was inappropriate.<sup>1,2</sup>

The people I tried to help were philosophical; they had lost nothing. But I felt I had let them down. I had not been able to relieve the pain after raising their hopes. Nor was I sure I had really understood their condition.

**Action Man**

Some years later, I was lecturing at a meeting in London. The applause seemed genuine, and the questions interested rather than simply polite. I could relax as I listened to the next speaker and look forward to supper. After all, The Royal Society of Medicine did a reasonable spread. It was a joint meeting of the neurology and rehabilitation sections, and the next lecturer was from Dublin, speaking on spinal cord injury. Nothing new there, I thought.

He began with a video of a man with a high tetraplegia, with no movement or feeling below the neck, competing in a paraplegic games. Unable to move much more than his neck and face, the man had a cross-bow mounted in front of him. He controlled its direction and elevation through a small mouth-organ device connected to the bow by a motor. He'd puff at one end, and the bow moved down; a puff or suck the other and it turned to the right or left. The film seemed old, and the man had the cropped hair, square-jawed look of a serviceman after the war. Slowly and with evident deliberation, he took aim, calculating the wind strength and the necessary elevation and direction, before he puffed into the center of the mouthpiece and shot the arrow.

I never saw if the arrow hit the target, and I remember little of the lecture. I sat there fascinated by the short film and by the way the man had interacted with the world. Though almost immobile, he had imposed his will and made an action—via the small mouthpiece—to unleash the arrow. He would have seen the hit and been delighted or frustrated by his aim, just as I would have, even if his body's involvement was reduced to his airway and lips, whereas I would have been standing, bow pulled back, arm outstretched, trigger fingers poised, eye in line, my whole body within the action.

In the second or so when he had broken his neck, that man had been transformed from a man of action, as a soldier or a lad about town, immersed in physical challenges, to an intellectual, able to exercise his mind and move a few facial, head, and neck muscles. The man, possibly a soldier, would have scoffed, "Me, an intellectual? Forget it." Yet, almost perversely, it seemed true. What he had previously done with his body, without a thought, was now beyond him. What he could do now

he had to think about deliberately and in new ways. How had he coped with the change, and how did he feel?

Most of us pay little attention to our bodies. They are usually absent from our awareness, just allowing us to do what we like. We walk, talk, sit, and write with no conscious attention to these acts. Our bodies are our instruments, the mechanisms of their functioning automated, and beyond our will or conscious attention. After spinal cord injury, the body is absented, insentient and unmoving, and yet has to be looked after, because it no longer functions automatically. People, I presumed, have to attend to their bodies in a wholly new way. Robert Murphy, in his moving and profound account of becoming tetraplegic, interestingly called *The Body Silent*, described this: “my former sense of embodiment remained taken for granted . . . my [new] sense of re-embodiment is problematic negative and conscious. . . . Consuming consciousness of handicap even invades one’s dreams.”<sup>3</sup>

Again and again, as we shall see, for tetraplegics, what previously took care of itself has to be known and looked after consciously, intellectually, and remorselessly, whether it is skin pressure care, bladder emptying, or bowel care, because those functions are no longer connected with their command centers in the brain stem. Those with spinal cord injury are condemned to an intellectual interest in their bodies in order to continue their lives.

At another level, we are aware of our bodies and take pleasure from our body, in exercise or a bath, or even during sex. We also have a conscious sense of our appearance, seen in our relations with others and in developing our self-esteem. What we look like and how we move, as well as what we say, play a large part in how we are perceived. In our emotional lives, as Merleau-Ponty wrote, “the body is more than a means, it is our expression in the world.”<sup>4</sup> For those with spinal cord injury, their bodies and hence their worlds might change. How?

In his famous essay “The Disembodied Lady,” about a person who had lost all sensations of movement and position sense from below the face area, Oliver Sacks described how, initially unable to control movements, she felt less “in her body.”<sup>5</sup> GL, with a similar but worse condition (she has lost cutaneous sensation as well as movement and position sense from the lower face down), has described how she feels like a pilot

of her body rather than in it. Her “deafferentation” is from the lower face, and she has to think to control her head and neck movements, a huge additional task. I have written about a subject and friend, Ian Waterman, with a similar loss of movement and position sense, and cutaneous touch below the neck.<sup>6</sup> He has normal neck sensation, and after an initial period of being unable to control any movement, has learned over years to stand and walk and to live independently. Ian does not consider himself disembodied—he is in and of his body. Interestingly, both he and GL have invested much time not simply in relearning locomotor and instrumental action, but also in relearning gesture. It was important for them to be emotionally expressive in their bodies.

Though Ian does not dwell on the time of his illness—it was more than thirty years ago now and a terrible time for him—it is clear that when, initially, he was lying on his bed and was completely unable to control movement in any way, he felt most disembodied. Ian described how, as he began to realize that he could control movement through thought and “visual supervision,” he began to feel more at home with his body. His re-embodiment seemed to require both a sense of making the movement and seeing that movement made successfully. In other words, a sense of agency or will,<sup>7</sup> as well as feedback of movement, seem necessary to feel at one with one’s body.

What, I wondered, did the man with the crossbow feel about his body? If sensation is reduced or even taken away from much of the body, and if movement, likewise, almost impossible, then he was reduced largely to observing. How might he view his body? More as an object and as a thing—if so, then where did he reside? Without movement, without gesture, without independence of action in the world, what was left of will? In his account of his own descent into tetraplegia, Robert Murphy wrote of the alterations that occurred in his will, even associated with a relatively simple movement: “For a while I tried to will the legs to move, but each futile attempt was psychologically devastating. . . . I was saved from the edge of breakdown because the slow process of paralysis of my limbs was paralleled by a progressive atrophy of the need and impulse for physical activity. I was losing the will to move.”<sup>8</sup>

The injury had altered his relation to his body and to others in huge and unimagined ways, from knowledge of his body to his will to move and his psychological integrity.

### **An Arm Full of Pepper**

For some time I had wondered about the pain that those with spinal cord injury complained of. How might that affect someone with no movement or sensation? Then I had a short burst of severe pain during a research visit to Germany.

We had arrived on the overnight train from Munich, groggy from a sleepless journey and still unsure why we had been woken for breakfast on the train at 5 a.m., leaving us two miserable hours of semi-wakefulness, watching a cold dawn light the snowy countryside. Rolf-Detlef introduced himself to us at Hamburg station and took us to his lab. Though still bewildered, we accepted his offer of another breakfast before he showed us around. It was clear that he was proudest of the laser used in some experiments on the perception and transmission of pain; in the wrong hands, he told me, it could cut through metal.

I was the first to do the experiment. Rolf-Detlef led me into a windowless room, where I sat facing a wall, with a low table in front of me. He explained that the pain would last sixteen minutes and I was to let him know its severity each minute. Then I felt a pinprick in the forearm as he injected the dose of pepper extract. Despite my preparation for the shock—let alone my desire not to put off my colleague, Ian, who was next in line—the pain made me gasp. My body hunched and my neck dropped. Ian saw despite my silence.

But I was not aware of all this; I could think of little but the pain. When the chemical went in I was aware of a short flush of warmth and then, almost immediately, came the pain. Television or movies sometimes show explosions as tiny areas of bright light that expand to fill the whole screen, destroying size and context and perspective as the screen fills. Similarly, my pain was difficult to localize; it was out there and below me, though I was no longer sure quite what that meant. It filled my arm, my body, and my sense of self. Pain destroyed my perspective and even my perception of me.

I had lived until then with a perception of my body as a whole. Even when not attending to it, I knew of and felt a presence of body, of an arm or a leg. But with the pain, I no longer thought in such terms. I had a pain that intellectually I knew was out there, but it took over so much

that further localization was impossible. More than that, however, I no longer had a background thought of my hand or arm at all. In an existential way, the pain removed my feeling of being embodied: I just had pain. My perception of a shaped arm and hand was absent, overwhelmed and driven from me by the pain. I could think of nothing. I may have slumped, I did not know; I just knew pain, pain filled my body and my self, with no room for other thoughts or feelings. I tried to explore and to analyze, but its grip was too great. I just existed, though quite what “I” was, I no longer knew; it was a me-with-pain, no longer an “I,” no longer a self observing the world or even immersed in it, for my immersion in the pain was so consuming that the world, as an external place to calibrate myself in, and from, no longer presented itself to me.

After a minute (was that all?), Rolf-Detlef called out for my pain rating. “Severe.” I shouted the same again a minute later. After that, thankfully, it peaked and I began to view the world and myself in it again. I could even observe the pain as it ebbed, rather than just exist with it. As my ratings of its severity subsided, I rejoined the others in the room, in the world. After twelve minutes or so, the pain was gone and I could joke about the “minor irritation” Ian was about to enjoy.

Ian did the experiment. I could see his discomfort and could empathize with him, with a matchless intensity and immediacy. Then Ian returned to our world and we broke for coffee. Some experiments, we agreed, are more fun than others.<sup>9</sup>

We went on to other experiments, and the pain faded from our view and memory.<sup>10</sup> That night, tired from a sleepless night and a busy day, Ian and I had supper together. We talked of much, but neither of us thought it worthwhile mentioning the pain. It was safely in the past, just another experiment. Yet over the next few days, I could not help but think about my pain; I had had a few minutes of experimentally induced severe pain, which I had known would soon be over. But what, I wondered, of the patients I had seen over the years with pain of varying intensities and durations? How inadequate had my response to them been? I had seen how little Ian’s expression communicated his pain. I would have had little idea of his experience if I had not just shared it myself. What of patients? How had they endured and communicated their pains? How had pain imposed on their lives?

## Nothing to Say

When I thought about my pain, I described the effect that it had on me but had no words for the experience itself. Are there no words for what pain is like that describe it exactly? Arthur Frank in describing, or attempting to explain his own pain, wrote:

We have plenty of words to describe specific pains: sharp, throbbing, piercing, burning, even dull. But these words do not describe the experience of pain. We lack terms to express what it means to live “in” such pain. Unable to express pain, we come to believe there is *nothing to say* [my italics]. Like a sick feeling that comes with the recognition of yourself as ill, there is a pain attached to being in pain.<sup>11</sup>

If pain was so difficult to express, even when we had all shared something of the experience, what of the numbness and lack of sensation of those with spinal cord injury? Were there no words for that, either?

I went to talk with a friend who works in a spinal cord injury center. I said I would like to sit with people with cord injuries to ask them how they cope and how they have learned new ways of living. I could see by his body language that there was a problem. Medical staff, he said, try not to get too deep, for that might lead to patients being confronted with something they could not face. I agreed that it might only be possible with those aware of my aim and strong enough to go the distance. But maybe many were. Robert Murphy had commented on this too: “Nobody has ever asked me what it is like to be a paraplegic—and now a quadriplegic—for this would violate all the rules of middle class etiquette.”<sup>12</sup>

I respected the feelings of those who worked with patients, but not convinced by my friend’s advice. After all, to live with spinal cord injury could not be done without, at some time, confronting it and coming to an accommodation with it. Chronic pain could not be ignored either. If not discussed with medical staff, then it would have to be with friends and family. I wanted to violate a few rules to try to understand. This is not to say that there have not been books on both conditions, and many fine ones, including Christopher Reeve’s, full of modesty and resolve.<sup>13</sup> But my aim was to look at a range of experiences of living with spinal cord injury, from soon after to years later, to understand what it was like.

It seemed a propitious time. Spinal cord injury medicine has not historically been in the forefront of neurological research. In the United

Kingdom, the hospitals for those with cord injuries have been sited well away from mainstream neurology wards and medical schools, in backwaters, hidden—until recently—from both public gaze and, alas, grant-giving bodies. That the situation is now changing is due both to the resourcefulness of those with cord injuries and to the fact that now, steadily, scientists are making important discoveries that may lead to new treatments.

The use of external neural stimulation of muscles, or nerve roots, or even the spinal cord may allow for far greater movement than people with spinal cord injury have previously had. At a more fundamental level, the old dictum that the adult nervous system is capable of little recovery once damaged may need to be revised, and several projects are underway to try to help patients recover function lost after spinal injury. The discovery of various nerve growth factors allows us to consider whether nerve roots may grow back into the spinal cord after injury and, after that, if the major pathways in the spinal cord may be helped to regenerate. Perhaps this is a false dawn, but it is nevertheless the first real dawn that the spinal cord injured community have had for some considerable time.

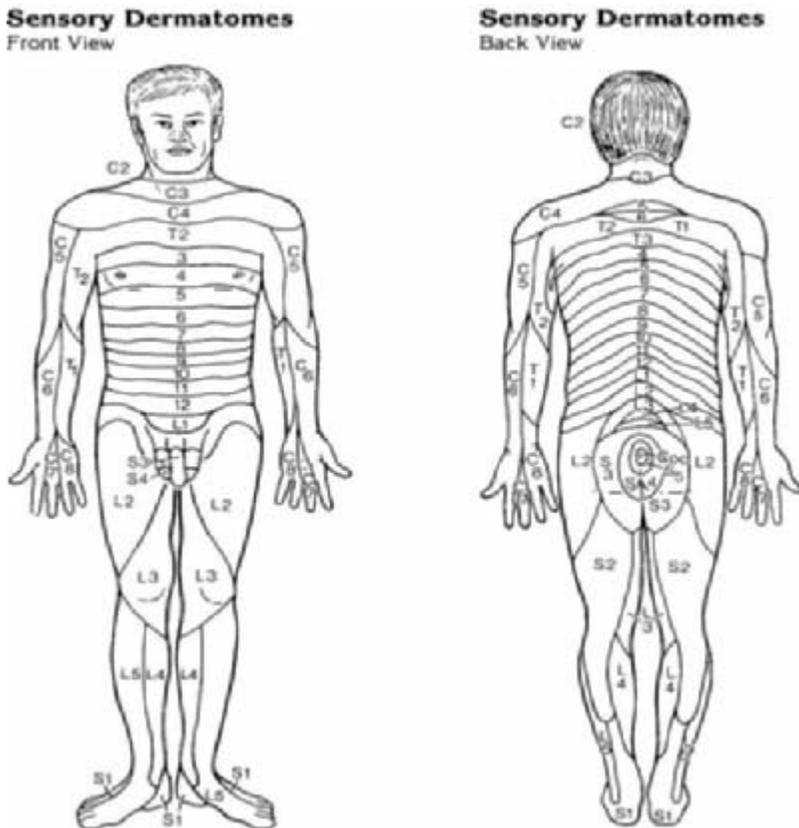
The fact remains, however, that for most people with spinal cord injury their problems have been present for many years and may well, unfortunately, persist for years, too. At one level, I was concerned to understand what it is like to exist with these conditions, and what sort of lives these people create with—and despite—their profound problems.

There have been many books involving neurological case studies; these neurological mishaps can certainly illuminate something of what it is to be human. Often such stories focus on the obscure and bizarre: losses of balance, or of sensation, neglect of part of one's body, blind-sight, and prosopagnosia. I am no less guilty than anyone else: I have written a book about a condition with fewer than ten known cases, and am happy to defend this.<sup>14</sup> Because of the fantastic nature of some conditions, a reviewer of one of Oliver Sacks' books went so far as to write that neurologists seem to have all the good stories. But more prosaic and common conditions such as spinal cord injury have much to teach us, if only we listen and look long enough. These stories are not appealing because the conditions are extraordinary or rare but because they reveal the responses of ordinary people to them.

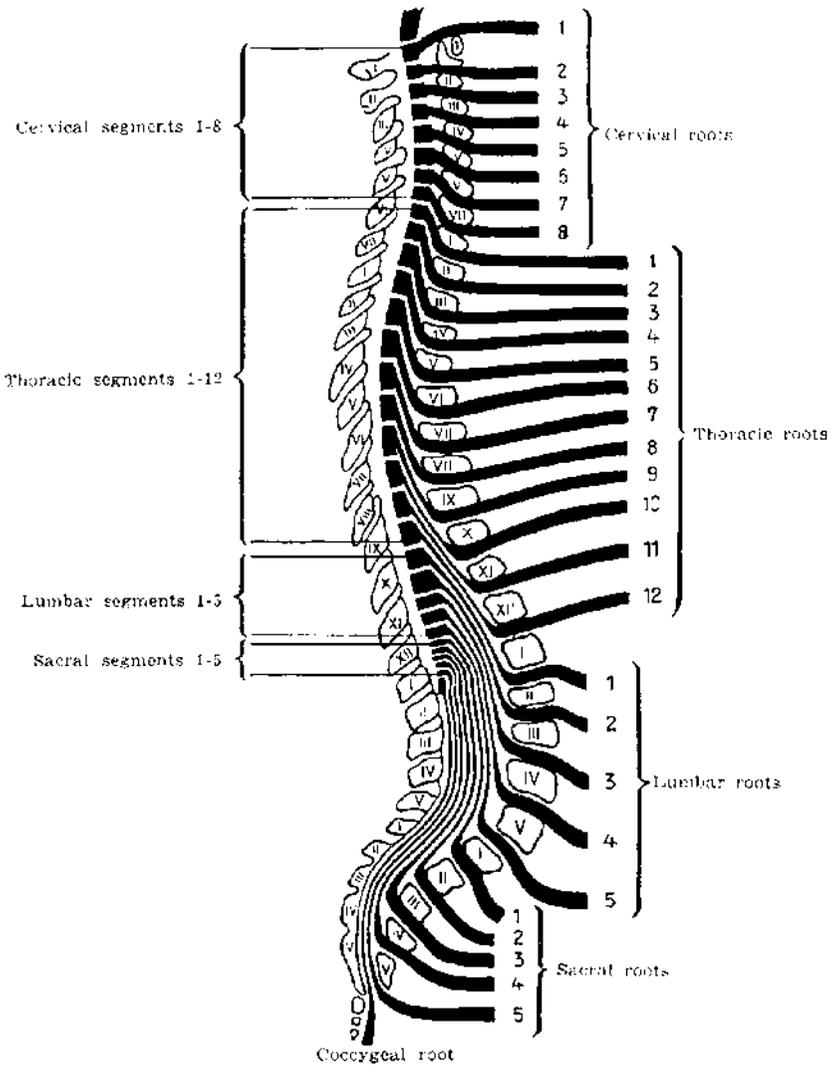
### The Physical Loss

No narrative of living with a spinal cord injury can be complete without some knowledge of the physical changes that occur as a result of the injury (see figures 1.1 and 1.2 and table 1.1).

The spinal cord begins at the neck and extends down to the low back, supported and protected by the vertebral column. The sensory nerves leave the cord and the motor, or movement, ones enter it through nerve roots at each vertebral level. These levels are broadly divided into the neck, or cervical (with eight vertebrae and eight root levels); chest, or thoracic



**Figure 1.1**  
Sensory levels; areas of skin supplied by each spinal root. (1989 Standards of the American Spinal Injuries Association. Reproduced by permission of the American Spinal Injury Association, Chicago, IL.)



**Figure 1.2**

The relation between spinal cord segment, vertebral column level, and spinal nerve root nomenclature. (Reproduced by permission from Guttman, Sir Ludwig, 1973. *Spinal Cord Injuries. Comprehensive management and research.* Oxford: Blackwell.)

**Table 1.1**

The relation between spinal nerve root level and various movements

<i>Movement</i>	<i>Spinal root level</i>
Diaphragm	C3 C4 C5
Shoulder out	C5 C6
Elbow bending	C5 C6
Elbow straightening	C6 C7 C8
Wrist bending	C6 C7
Wrist straightening	C7 C8
Finger straightening	C7 C8
Finger bending	C7 C8 T1
Hand muscles	C8 T1
Hip bending	L1 L2 L3
Knee straightening	L3 L4
Hip straightening	L4 L5 S1
Foot lifting	L4 L5 S1
Foot pointing	S1 S2
Toe movement	L5 S1 S2

Note that each movement is dependent on more than one root and that most roots contribute to more than one movement.

(twelve roots); low back, or lumbar (five roots); and pelvic area, or sacral (five roots). The level of an injury is described in terms of its root level, with a high cervical injury being, say, C3, and a low back one L5. An injury in the cervical area will lead to loss of use of arms, trunk, and legs, a tetraplegia if complete, or a tetraparesis if some movement remains. Injury to the thoracic, lumbar, and sacral cord leads to loss of movement of the legs but spares the arms—paraplegia if complete, and paraparesis if incomplete.

Any spinal cord injury may be temporary or permanent. Most injuries involve some initial swelling as well as more serious damage, so some recovery may occur, which is one reason why prognosis can initially be difficult. Because the cord is arranged, in cross section, with nerve fibers involved in touch and movement sensation in its upper half and those fibers involved in movement and pain and temperature sensation in the lower half, it is possible to have a cord syndrome with loss of movement and pain/temperature sensory loss but some touch sensation remaining, or one in which movement remains but touch and movement and position sense are lost. Usually, though, the impairment is not so neat as this, and some or all of both are affected to varying amounts.

The functions of the cord are reflected in the neurological impairments following damage to it. These may be divided into movement or motor function, to voluntary muscles as well as to the breathing system, gut, bladder, and blood vessels, and sensory function to skin, muscles, and internal organs. Because different sensory and motor nerves pass in and out at each level and because the cord is the relay of fibers to and from the brain, the level of injury is crucial.

Those injured at C1 and C2 will have no movement and sensation below the head. They will be dependent on a respirator because the nerves controlling breathing exit at C3. C3 tetraplegics may be able to control an electric wheelchair via a head control, but will still need assistance with breathing. Someone with a C4 level may be able to breathe unaided using the diaphragm, though he or she (and anyone with an level above T8 or so) will still have lost chest wall movement and have reduced expansion of the lungs. A C5 lesion will allow some movement of the shoulders and of biceps, allowing elbow flexion, but no power to straighten the elbow. C6 adds movement of the wrist upwards, though still not use of the hands. A person may be able to transfer in and out of a wheelchair. A C7 level allows independence with elbow extension aiding transfers, though finger movements that are controlled by C8 and T1 are still not normal. For a C8 tetraplegic independence might be expected.

In thoracic injuries and below, people are paraplegic. In T1 to T8 lesions, trunk muscles as well as chest wall breathing are lost, leading to difficulties in balance in a wheelchair, which are shared with all tetraplegics. In addition, the abdominal muscle are also paralyzed, leading

to the tetra tummy, a lax and large abdomen that can be so dispiriting. Lesions around T8 and below have effects mainly on leg and hip muscles.

In a complete spinal cord lesion, all sensation is lost below the level, and because people do not feel, they can injure themselves without awareness. They have to be aware of skin care to prevent burns and, especially, pressure ulcers. People in wheelchairs often do this by lifting the torso a few inches from the chair to allow temporary relief for the skin over the buttocks from the weight of the body.

The control of bladder and bowel is coordinated at S2 and below, so anyone with a complete lesion above this will be incontinent. Men usually have either an indwelling urinary catheter or introduce a catheter intermittently (without sensation, of course). Women usually need the former to prevent incontinence. These increase the chances of a urinary infection, and kidney and bladder stones and renal failure must be guarded against. The bowel can be trained to empty fairly regularly, or be evacuated manually.

Sexual function is coordinated at similar levels to the bladder. Men with complete tetraplegia may experience spontaneous erections, through intact spinal reflexes in the sacral cord, but may be unable to become erect in the usual ways. Those with low sacral damage may not be able to experience erections because the local spinal and nerve reflexes are damaged. For women the lack of erection may be less of a problem than the loss of sensation.

In addition, there are a number of other functions altered or lost because of spinal cord injury. Temperature regulation can be a problem in tetraplegics, because they cannot shiver, sweat, or control blood vessels' dilatation and constriction below their level. The latter may also be the reason for autonomic dysreflexia. In these, seen in those with levels around T6 and above, large increases in blood pressure can suddenly occur, which present as severe headache and sweating over the forehead caused by dilation of the normally controlled blood vessels of the head and neck, connected to the brain by the intact cervical cord, in response to a rise in blood pressure following, say, a problem in the area of body below the level. Bladder dilation is a potent cause of this, but some people have dysreflexia during rehabilitation when they are first raised to the vertical. This is a medical emergency, with stroke a real possibility if the blood pressure is not reduced. The rise in blood pressure is all the

worse because tetraplegics normally live with lower blood pressures than able-bodied people.

Muscle spasms can be a real problem in those with levels above the lumbar cord. Initially after spinal injury there is a loss of all reflex activity, known as “spinal shock.” But then, over months, reflexes become abnormally active, which can lead to huge spasms in response to relatively innocuous stimuli.

Lastly, as we will see, people with spinal cord injury have to live with a variety of pain. Roughly 60–65 percent of people have pain, and in 20–25 percent it is severe. This may reflect damage to the nerve roots at the site of the lesion, or elsewhere—after all, an injury sufficient to cause cord damage may also have caused damage in the nerves in the shoulder or elsewhere. Later it may also be the result of shoulder arthritis after years of transfer from chair to car, for example. Lastly, one of the most troubling types of pain is “phantom” pain, perceived in the area of the body below the level of cord damage in an area that cannot be felt. This may be similar to phantom limb pain, as in both cases the brain is disconnected from the area in which pain is felt.

Thus the cord damage may differ in completeness, duration, and most importantly in level. Most of those I interviewed have a complete spinal cord injury in the cervical region. The neurological impairment confronts each person with a huge loss. As we will see, however, each person’s response to it varies hugely.

### **The Simple Questions**

There are many books on the science and medicine of spinal cord injury and, excitingly, more and more papers on research. But my aim was different and complimentary, to ask the simple question of what it is like to live in a wheelchair, without sensation and movement in the body. The answer is found in the experiences of those in that position, but in fact there is no single answer, for each person has different responses to their injury.

I have chosen twelve narratives of people with similar and in some cases identical impairments, but with differing experiences. How individuals responded to their new way of living has shaped the division of the book into six main sections.

It begins with the narratives of two men, each injured over twenty years ago. Though very different characters, their accounts overlap in revealing the continuing grip of spinal cord injury. These accounts may confirm something of the worst of this impairment. It seemed important, at the start, to consider tetraplegia as a huge and continuing disruption in the normal, effortless flow of life.

After these raw narratives, there is a short commentary on some aspects of the experiences of Graham and Colin. Their spinal cord injuries reveal how our bodies normally enable us to make our way in the world with little attention to them. These two men can never forget the need to care for their bodies and so never forget their spinal cord injury. It continually imposes on their waking lives, conditioning their view of the world and their view of themselves.

In the next two narratives, David and Ian, over widely dissimilar time courses, come to terms with their injuries and begin to explore ways of living. David, a young university graduate at the time of his injury, managed to live by ignoring his tetraplegia as best he could for several years before he was forced to consider it, due to illness and erroneous advice. He came through and began to explore independence and a far richer life. Ian's story, in contrast, is not over decades but over one year, and yet he too moved to an exploration of the remaining possibilities and choices open to him, with some surprises along the way.

There follows a short commentary on these two narratives, focussing on those areas raised by David and Ian's narratives. David at one stage contemplated suicide. Able-bodied readers might not find this surprising, given his tetraplegia. But, as will be seen, this thought was a response to far more complex matters than his spinal injury. After this, the experience of severe pain, which Ian has had to cope with, after injury is considered.

After such maudlin matters, it might be a surprise that both David and Ian find enjoyment and indeed some contentment in their lives. In fact, the quality of life of most people with spinal cord injury is good. They show ways of exploring and then coming to an accommodation with spinal cord injury; this forms part of the remainder of this commentary and is implicit in the remainder of the work.

These men were all well aware of how they could not inhabit their own bodies, how they could not be "in the flesh." In the next two chap-

ters, I talk with two women who have had different functional electrical devices implanted, one to enable the return of hand function, the other, more ambitiously, for standing. The devices offer Deborah and Julie the possibility of choice and of control of parts of their bodies that were otherwise beyond their control and action. How has this affected the way they view their bodies?

Illness and impairment never affects one person alone; it always affects family and friends. The family members, though not suffering the illness, can be underinformed and left out of the loops of care and treatment. In spinal cord injury, when the patient is often in the hospital for months learning new skills and needs, this can be both an acute and an enduring problem. When the patient is also left with severe chronic pain, it can produce intolerable pressures. The next two short chapters are the recollections of two people whose spouses were injured. Unfortunately, they have differing outcomes.

The history of successful treatment of spinal cord injury is not long. Though spinal injury is recorded on papyrus scrolls, until the beginning of the twentieth century those with such an injury usually lived a few months, often rotting in side rooms of hospitals as they died of pressure sores and infection. For Sir Ludwig Guttmann, the founder of Stoke Mandeville Hospital and the pioneer of care in this area, spinal cord injury was “the most depressing and neglected subject of all medicine”:

If the spinal cord is severed or crushed . . . this immediately results in a paralysis below the level of the injury, with loss of most essential functions . . . all motor functions, appreciation of all forms of sensation, and results in loss of posture and control of bladder and bowels. Sexual function in men is abolished. Women lose sexual sensation but can have intercourse and still conceive. In injuries of the cervical cord, the respiratory function as well as the blood circulation are greatly impaired, especially in very high lesions, the involvement of the blood circulation leading also to a reduction if the tone of all tissues, especially skin and muscles. This, in turn, results in a lowering of their resistance to pressure, which is one of the most important causes of the development of pressure sores.

They did not establish a social problem in the past, as their life expectancy was very short, two to three years at the utmost was the rule.<sup>15</sup>

Most actually lived less, with survival at the time of the First World War being a few months for most. Only 20 percent survived three years. Little happened subsequently until Guttmann arrived in Aylesbury. He

found, with rigorous attention to pressure areas, to bladder infections, and to nutrition, that paraplegics (and then tetraplegics in the subsequent years) could be salvaged and given up to twenty extra years of life. But even then, as Guttmann also realized, “Most of those who managed to survive were doomed to spend the rest of their lives as pensioners at home or in institutions for incurables, dependent on other people’s assistance, and as a rule, given no incentive or encouragement to return to a useful life.”<sup>16</sup>

Following the miraculous work began by Guttmann and then taken up throughout the (developed) world, people with spinal cord injury had their lives extended by decades. But, arguably, social issues lagged behind these wonderful advances in medicine. How were people with spinal cord injury to live in society? They needed somewhere to go, because hospitals could not cope for such long periods. Many went into institutions; at the time, they were seen as a great advance, though now, for some, these homes are seen as delaying death more than prolonging life.

Over the last forty years there has been a movement, led by those with spinal cord injury themselves, for people to move from care homes to living in their own homes, either with their family or alone. Paraplegics and tetraplegics have continued their careers, allowing financial independence. This has been possible in part through the use of personal assistants at home and work. The book’s next two chapters concern the narratives of two of those active in pushing for these reforms and for a move from a medical model of neurological loss and dependence to a more social and empowering one, with huge implications for how spinal cord injury is viewed. Given the energy of Stephen Duckworth and of Michael Oliver, one occasionally has to remind oneself that both are tetraplegics.

Both are also hugely eloquent, and the next chapter discusses their views on neurological impairment. The need for work as a way of gaining independence, how best to influence others to change society’s view of “disability,” and how the disabled can draw attention to their problems without being defined by them are debated.

After the fireworks of Stephen and Michael, the last section is quieter, deliberately so. These two chapters tell the stories of two young men who live with tetraplegia as nuisance rather than as tragedy. Nasser and

Tony's experiences reveal lives that have been able to move beyond endurance to those who manage, almost, to transcend their impairment. The lack of drama with which they relate their lives is, arguably, the most remarkable thing.

The final chapter attempts to bring some observations together and to explore some of the implications of living without movement and sensation. It is, for instance, most important to be able to manage friends and relations, familiar with you but not with spinal injury. Independence for tetraplegics is often due to the use of personal assistants. The chapter considers this curious relationship between physically active PAs and their employers. In fact, this commentary focuses on relationships: between carer and employer, tetraplegic and others, and finally tetraplegics and their altered bodies and new lives.

Talking with those with spinal cord injury and with pain, one public, one private, one an unsought absence, the other an unwanted presence, may allow different perspectives on the same thing: our relation to our bodies. Few have attempted to answer the simple questions of what it is like to live with spinal injury, because these seemed the most difficult to ask. Though I discuss theoretical and clinical aspects of the condition, it is to these simple questions that I will return again and again.

When I first encountered tetraplegics, I was fascinated by the way they carried on their lives and the ways they endured with their impairment. I spent time with some and, as guys do, discussed sport and life in general. But as a doctor doing research with them, I could never find the words or the way to talk to them about the things that interested me. I guess I was in a hurry with the research and the papers and with the next thing.

Now I have gone to people, not with a white coat or a stethoscope, and without any promise to help or assist. I have gone to listen to their lives as they express them in their own time and in their own homes. Now, I hope, I have found the words.

### **A Word or Two on Names**

In the United Kingdom, spinal cord injury at the level of the neck and leading to paralysis of the arms, legs, and trunk is known as tetraplegia,

using the Greek for loss of use of four limbs. Paralysis at the chest or lower back level leads to paralysis of the legs and some trunk muscles, sparing the arms. This is known, again after the Greek, as paraplegia. In the United States, the more familiar term quadriplegia is used, combining the Latin for four, quad, with the Greek word for paralysis. I have kept faith with the English, partly out of desire to maintain the purity of the derivation, partly out of my preferring the sound and look on the page of the T term over the Q one, and partly, others might suspect, from childish nationalism. I suspect, as in so much, that the American usage will prevail. Paraplegia can be used as a generic term for both tetra- and paraplegia. In this book I will not use this shorthand. In fact, the people whose narratives are told are all tetraplegics except for two, so one hopes this will not be confusing.

Though numbers are not a major concern, some idea of the incidence of spinal cord injury might be of relevance. It has been suggested that there are 183,000–230,000 people in the United States with such an impairment, with 82 percent male and most, 58 percent, aged between sixteen and thirty. Young people tend to be injured on roads or in violence. There may be a second peak in old age, when falls become more common.<sup>17</sup>

I began by talking and writing, always, of “people with tetraplegia,” and never about “tetraplegics.” This form of political correctness was designed to show that each person was an individual first and foremost, with his or her neurological impairment seen secondary to himself or herself. Then I met several people who were proud to be “disabled” and viewed their identities as being intimately related to their tetraplegia. They were more than happy to be defined by their impairment and to be “tetraplegics,” and even were unhappy with my liberal PC use of words. So some are happy to be “people with tetraplegia” and others prefer to be tetraplegics. I have therefore used both terms and worried less. If I have used the wrong form of words in relation to a given person, I apologize.