

INTERLUDE

With one hand she holds tightly to the support bar along the wall of the bathroom. I take her other hand gently in mine, wash each finger, noting the smoothness of her skin, the beauty of her long, slender fingers. “My finger nails” she says “they’re dirty”. Without speaking, I run my index nail, covered with a washcloth, under each of her nails, systematically snapping out the dirt as I go, hoping to wash away the lingering smell of faeces, urine, perspiration, bile bags, plastic tubes, stale hair oils and hospital odours. It’s a good sign that she cares. Until now, she hasn’t been that concerned even about urinating in bed.

She extends her arm and I slowly wash from wrist to shoulder, observing the intrusion of the spreading, black bruises marking needle points. Her washed hand holds onto my wrist for support now as I unclasp her other hand from the railing. I repeat the process on that side, looking at the new scars from the gall bladder surgery

“I’m going again”, she says, sucking in slowly through open lips and closed teeth, eyebrows raises as though she is asking my permission and apologizing at the same time. I’m glad she is sitting on the toilet. It’ll be less of a mess than before. “That’s OK” I respond. “Maybe this will be the last time. Hopefully the laxative has run its course”. Then “I’m sorry about last night” she says. “It seemed it was every hour. You shouldn’t have to do that” . “I didn’t mind” I say, remembering my reflex gag reaction the first time her bowels exploded in the night. Only the determination that she not know how much the smell, that rotten, chemical odour, bothered me kept me from adding my regurgitation to the brown liquid I poured into the toilet. “I’m glad I was here”. “The nurses don’t come right away. Even with you here, some ended up on the bed, didn’t it?” “Yes” I said “but now we know better how to do it, get the bedpan under you sooner”. “If anybody told me I’d have to be doing this”, she grimaced. “You used to do it for me” I remind her. We laugh, like two good friends sharing a memory.

I observe from a distance almost. Her body is my body, my body in 36 years. So this is what it will look and be like. I see. My pubic hair will be thin and grey like this, I think as I notice hers. Then I walk away to give her the illusion of privacy.

“Are you ready to get back in bed now?” I ask. “Yes I’m worn out” I extend both arms. The bile bag pinned to her gown threatens to become entangled in our embrace. “Put it round my neck” she suggests. “It’ll be a necklace”. I grin: the humour makes it easier to refer to the bag. She looks into my eyes as I walk backwards, to pick up my cues, when to move forward, when to turn. We are intimately connected, totally trusting. She sinks back on the pillow, and sleeps.

Carolyn Ellis (2004) “The Ethnographic Eye: A methodological novel about autoethnography”. Alta Mira Press

BETWEEN THE LINES

“As the paralysis has crept upwards and outwards, numbing sensation, and imprisoning movement, my dependence on Yolanda has become complete. A typical day starts when she awakens me at 8.00 a.m. and removes my night tray with its array of support gadgetry. She then washes the lower part of my body, that means rolling me first on my right and then my left side, into a position to ease me onto the hoist that picks me up and shuttles me from place to place. Yolanda then pushes the lift over to the wheelchair and lowers me into it. Then I go to the bathroom for the next stage of my ablutions. Yolanda must first squeeze the toothpaste tube, my grip isn’t strong enough any more. Since I cannot lean forward over the sink on my own, she has to push my head over it so that I can rinse my mouth afterwards. She then gets my shaving equipment ready, and I do the rest. Total time for the morning routine is about an hour. In a very real sense we are both held in thrall by my condition – we are each others’ captives.

Such dependency is more than simple physical reliance on others, for it begets a kind of lop-sided social relationship that is all-encompassing, existential and in some ways more crippling than the physical defect itself. It is not so much a state of body as a state of mind, that warps all one’s other social ties and further contaminates one’s sense of who one is. Dependency, especially in the West, invades and erodes the very compact upon which association between adults is premised. Lack of autonomy and unreciprocated dependence on others bring debasement of status.

Many strains have stolen into our marriage because of my disability, but they are occasional rather than constant, and we get along better than most couples. Since I know that Yolanda is overburdened, I generally hesitate to ask for things and feel slightly guilty about bothering her. As a result I’m especially sensitive to the tone of her response. Do I detect a note of impatience? Is she over-tired? We’ve been married long enough for me to pick up the cues rightly, but I alter and magnify them, interpreting a small note of fatigue as a major resentment and reading rejection into a fleeting expression of annoyance. In turn, Yolanda often reads a peremptory quality into my requests, and answers by saying “Can’t it wait? I’m busy”. There is usually a tacit truce, a moment of silence and we resume conversation as though nothing had happened. But there is a heightened self-awareness and guardedness in our relations that wasn’t there before, and that has reduced openness and spontaneity. Our very attempts to avoid conflict through tact and delicacy have become part of the problem, not its solution.

The inroads of fatigue and overcommitment produce anarchy in Yolanda’s everyday affairs. Her plans are never clear and stable, and she verges on panic as she runs from one chore to another. One might well ask why she doesn’t quit her teaching job. But her career is her last remaining bastion, the only activity that is uniquely hers, the one involvement that defines her as a person rather than an unpaid nursemaid. And she loves her job, it is an avenue of escape from me and my troubles. But she still fears that my needs will eventually force her out, leaving her a prisoner of the house – and me.

From: “The Body Silent”. Robert Murphy (1987). J.M. Dent.

FRAGMENTS

“They’ve got their own lives to lead”

Once the family’s grown up and left home, you get into your own environment, you speak to them, you phone them, but you’re not I never have been a one for going in and out of people’s houses. Never have been all the years I’ve lived here, unless I was really needed. When they were children, maybe, but since then no. I think we’re just growing old and that’s it.

“I certainly wouldn’t ask a relative to help. It’s too emotional a situation, I can – and do - put up with a tremendous amount, but I couldn’t expect a relative on either side to be able to come and cope with things or do some of the physical requirements, for obvious reasons. It’s OK for me to do it, but not someone else. I mean I’ve got to do manual evacuation of her bowels.

I daresay all I’ve got to do is go down and knock on the door or pick up the phone and say ‘Would you come up’ ‘cos I mean our son’s said time and time again ‘Mam if you want any help you’ve only got to phone’, but I don’t want the two of them to see their dad like this where he can’t help himself”.

Help from formal services

“The hospital offered me anti-depressants because sometimes I get a bit gloomy, but I asked my GP his opinion, and I quite like my own GP, in fact as the medical profession goes, he’s not bad, and he said in his opinion I didn’t want anti-depressants because, to put it bluntly, he said ‘Well in your position you’re entitled to get pissed off”

“All of a sudden, you know, I mean I’d coped with the disability and illness all the years and accepted .. well I’d say accepted some of them. And when more and more come, I just didn’t want to. It was as if I’d had enough, I didn’t want any more.

“I think it would be helpful if people in my situation were told what was there for them, instead of being left to plod on and find out. I mean money isn’t everything but it certainly makes life more comfortable.

“I know the occupational nurse comes from my husband’s work but she more or less talks to him, she’s ever so nice, but I don’t actually have anybody who’ll come and talk to me, hear my side of things”

Gillian Parker “With this Body: Caring in Marriage” Open Univ. press: Buckingham.

And reflections on independent living

“There seems to be a split between needs and wants, days out are a kind of a want and you can really do without them. I just feel that it’s not unreasonable to have the occasional social event, because it’s something that non-disabled people would take for granted, wouldn’t they”.

“I have two personal assistants working for me and basically they can do anything that I need doing.. The advantage of that is that you pick somebody ... I know who’s coming .. it’s a matter of choice and flexibility. And if I needed the extra hours, I could ask one of my P.A.’s to spend a whole day with me if that’s what I wanted for that particular day, so it gives you more of a choice”.

“It means that the things that I need doing I can get done without feeling it too much as an invasion of privacy. I feel it’s very much helping me to be independent. I did feel, when we first realised that we really had to have somebody come in, that it was an invasion of privacy. But it’s really nice being able to choose somebody myself, who I wanted, when I wanted them to be with me, where and when I want them. And what I actually want”.

“We want to choose the time we get up, we go to bed, we go to the toilet. We want to be able to choose who gives us the personal assistance we need, how we receive it and where we receive it. I short we want to be able to plan how we spend our time without the constraints of fitting into the existing care system”

“ Trouble is, where are these people? And even if you find one that’s really sensitive, you know attuned to you, they don’t stay long. You no sooner get used to someone than they’re off, and you’ve got to do all the instruction all over again. You’re responsible for hiring and firing too, it’s like being a manager in your front room!”

Vernon A. and Qureshi H (2000) “Community care and independence: self-sufficiency or empowerment?” Critical Social Policy, 20, 255-276

