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Home

Those of us in post-industrial economies will die relatively slowly in old age, probably from cardiovascular disease, cancer, respiratory disorders or the ‘prolonged dwindling’ that is dementia and frailty.¹ As our functional abilities decrease over time, it is likely that we will receive at least some part of our care in the home. However, the proportion of home deaths has been falling. It is estimated that if current trends continue, fewer than one in ten of us will die at home by 2030.²

Care at home is a complicated business, described by the think-tank Demos as sometimes being a ‘blizzard of disconnected services.’³ This blizzard of care is spread out across the public, voluntary and private health and social care sectors, among personal assistants, General Practitioners (GPs), Clinical Nurse Specialists and district nurses, social workers, health advocates and occupational therapists. Current government policy aims to encourage more home deaths and to provide palliative care to all those who need it, regardless of their diagnosis.⁴ Yet evidence suggests that there are numerous problems in accessing palliative care. These include local variations in what palliative care services are able to offer and a lack of awareness of palliative care services among those from socially disadvantaged groups.⁵

Unlike the care that is provided in institutional settings, care in the migrant household not only rearranges the time and space of what is private and what is intimate⁶ but also what is *here* and what is *there*. ‘In the aggregate, the global household produces and distributes a large quantum of social wealth in the form of unpaid household labor, household-based business income, monetary and in-kind remittances, and gifts,’⁷ the feminist economists Mahila Safri and Julie Graham have pointed out. Alongside these hidden relationships are small

revolutions and redistributions in domestic power between carers and ill persons.

Body work

Figure 11.1 At home.

Courtesy: Nadia Bettega

A blade of sunlight makes an incision into the darkened room, illuminating the Hindu gods Shiva and Khrisna who are keeping watch over him.

For the past year Mr Gupta, a Bangladeshi Hindu, has been confined to his bed. The ecstatic language of his grunts and rasps is unintelligible to me. To his wife, and two home carers, the distilled sounds are heard in Sylheti as concrete interjections – ‘He is asking where his wife has gone,’ ‘He wants to go to the

toilet'. This call-response relation is peeling itself away from the parochialisms of language and culture. Mrs Gupta feels that she is the only one who is truly fluent in this evolving sensuous dialect, the intricate gestures of face and fingertips, how his eyes listen, talk and touch.

Each small communication is a resounding sign of Mr Gupta's continuing being in the world. Perhaps this is what the philosopher Jean-Louis Chrétien meant when he wrote of the soul's appearance at the skin's surfaces, of how the human voice can be gripped by the 'superior force of a bidding that nonetheless would never materialize without its vivid deficiency'.⁸

Sahab and Iqbal, Mr Gupta's home carers, visit three times a day: one hour in the morning and in the evening and for 30 minutes at lunchtime. This is the amount of care that Mr Gupta has been assessed as needing by the local authority. In these two-and-a-half hours they provide 'personal and social care' that is means tested. It includes some cleaning, lifting, washing and 'bottom cleaning' as Iqbal explains to me through an interpreter. This type of care has been called 'body work': 'employment that takes the body as its immediate site of labour, involving intimate, messy contact with the (frequently supine or naked) body, its orifices or products through close proximity'.⁹

Sahab and Iqbal work with little verbal communication between each other. They are accustomed to the tacit rhythms of this body work: who will do what, when and in which order.

Figure 11.2 Shakti.

Courtesy: Nadia Bettega

The carers don plastic aprons and latex gloves, using a red plastic bowl of warm soapy water and a small red flannel, to wash Mr Gupta. Sahab and Iqbal alternate between facing each other and working side-by-side. They use the mechanical bed to raise and lower Mr Gupta's upper torso. Sahab will hold one of Mr Gupta's

arms in the air, gathering in the fingers and supporting the wrist while Iqbal washes Mr Gupta's armpit.

The colour red is significant in the Hindu religion. It is an auspicious colour. The colour of *Shakti* (prowess).

In washing Mr Gupta the carers need to work with sensitivity to what they see and to what they can feel, hear and smell, which can change daily, and also within the same day. As Mr Gupta's disease progresses, his body has become more heavy and lifeless. He appears as someone caught in a deep and irreversible woozy state, somewhere between sleep and awakening. To Mrs Gupta, her husband is still very much present though locked in.

To wash their charge thoroughly and to minimize any discomfort for an interred subjectivity, the carers must learn to work on, with and around the idiosyncrasies of each disabled body and its prostheses. They do this by applying and then modifying the skills that they have been taught, and in accordance with the body wisdom and preferences that are passed onto to them by each of the people that they care for. These are relatively small things, perhaps how a person likes to have their back rubbed or their ankles elevated so that they do not rub on the sheets.¹⁰ Ultimately, they must learn the sensual terrain of each body in situ, working with its resistant forces, varying sensibilities and dispersed weightiness, building up an intimate hands-on knowledge as they go. At times 'corporeal anticipation'¹¹ – of flailing hands or of a body's habitual listing to one preferred side – will take over; a firm steadying arm is extended across a body just before it crumples or falls.

All the time that they are tending to him, Sahab and Iqbal watch Mr Gupta's face and body for signs of distress or discomfort. They talk to him in Sylheti, moving between a regard for corporeal surfaces and an interior life where cultural decorum and deference to elders must also be attuned to. Only as the flannel moves downwards does Iqbal break eye contact, fixing his gaze on the flannel, a civil inattention and emotional middle distancing that is practiced in intimate medical examinations,¹² minimizing embarrassment for all parties.

The red flannel that moves over the vulnerable body is charged by a delicate *Shakti* where warm water and multiple sensibilities wash over Mr Gupta.

The care provided by Sahab and Iqbal is paid for through a 'personal budget' allocated through a direct payment scheme from the local social services department. Direct payments are part of a care agenda of personalization that in this case was further mediated by a local non-profit Bangladeshi community organization.

Figure 11.3 Washing bodies.

Courtesy: Nadia Bettega

With each visit Sahab and Iqbal do much more than personal and social care. They bring with them freshness and temporal rhythms, a breeze from the outside world where clock-time and tempo still have meaning. Both men are recent migrants from Sylhet who have left rural villages and families to marry British Bangladeshi Muslims in the East End of London. Iqbal says that his caregiving is not like a job. Despite their religious differences, he feels a part of the family of this childless couple. It is as if he is fulfilling a son's duty to his father.

This tendency to align or to naturalize care work as a kin relationship is a double bind. It contributes to the devaluation of the work – it is not 'real', skilled work – and it can compensate for low wages. On his day off, Mrs Gupta tells us, Iqbal sometimes does the shopping for them, as well as other small extras, such as picking up a prescription; tasks that are not included in the rationalized economics of their care plan. Iqbal is more like a nephew she says.

Nobody in the room speaks English, except of course Mr Gupta. Mrs Gupta had been a nurse in Bangladesh but she was too ashamed of her lack of competence in English to try to re-qualify and to practice her profession in the United Kingdom. Instead she took up unskilled jobs, often sewing with other Bangladeshi women in the East End factories that are the hidden powerhouses

behind the high-fashion designs worn by celebrities across the globe. Without children or extended kinship networks, Mr Gupta was to become her only means of contact with life outside of the Bangladeshi community in East London.

As Parkinson's disease has taken away his mobility and strength, the more intensive care that Mr Gupta needs has brought with it unforeseen, if precarious, opportunities. It has revived Mrs Gupta's world, while providing a vital livelihood for Sahab and Iqbal. The reciprocal dependencies that characterize the emergence of these new segmented linguistic and ethnicized markets within the global economy of care are another facet of the ambivalence in home care. The intimacies of body work, together with shared social and linguistic exclusions for both care recipients and caregivers, spawn and encourage the kinning of paid care. Yet the very nature of care within the home, its physicality and emotional labour, a resistance to seeing it as a job with specialist skills, choices, boundaries and career development, contribute to making it a vulnerable, low-status occupation that is especially difficult to unionize.¹³

The care workforce in the global North is increasingly made up of migrant women. According to the United Nations, women now constitute half of the international migrant population. They are a part of what is called the global care chain 'where migrant women from poor countries fill the gaps in care activities in richer countries in order to send money to other women left behind in the country of origin who take care of their family members, often through unpaid family labour.'¹⁴

As first-generation migrants age, the demand for same-sex personal care for some cultural and faith groups is opening up economic opportunities in the care sector for men like Sahab and Iqbal who tend to be employed by community, consumer and advocacy groups. New unforeseen opportunities are also being created for women in the households of declining patriarchs.

Slowly, slowly

Mr Balani is a Gujarati from East Africa, living in the Midlands. He has diabetes, cardiovascular disease and dementia. He is cared for at home by his wife, with help from his daughter Pavita. Our interview took place with the three of them together. I speak neither Gujarati nor Hindi. Even though Mrs Balani speaks English with fluency, she thought she might not be able to express herself fully without her daughter's help. Around this crowded interview the circumstances of everyday home caring encircled us, where bodies as much as

objects – wheelchairs, walking frames and commodes – become conjoined and herded into small spaces so that it is difficult to avoid bumping into things and each other.

Mrs Balani began by describing her husband's *day-by-day* descent into incapacitation over a period of ten years and how his dementia had eventually led to the ruin of the family's small business and the loss of their home. The story was interspersed and supplemented by Pavita, so that each narrative spoke to and modified the other, producing something new.¹⁵

Mrs B: After the stroke he was OK a couple of years and then he started day by day-

Pavita: He started with a walking stick and losing his memory and not recognizing people and his speech slowed down. That's it, slowly, slowly and now his complete care is actually twenty-four hours.

Yasmin: So is that what you have now, you have twenty-four hour care?

Pavita: Well she doesn't have twenty-four hour care. She's the carer, it's just that they live on their own and they've got a day centre in the morning. First thing in the morning actually somebody comes to give him a bath, then he goes to a day centre and then he comes back like at four o'clock and between five-thirty and six Chirag comes again, because every time he needs to take the medication, somebody's got to be there, otherwise he can get quite aggressive.

As the story was unfolded, passing back and forth between the women, moving between three continents, and all the time across a mute Mr Balani, the dialogue began to dovetail with the rehabilitative equipment surrounding us, an apparatus and aid supporting a faltering, and at times painful conversation about the reshuffling of power within a debilitated household. Interviews can sometimes be used in this way, as a space from which people can voice and explore difficult topics, apparently for the benefit of the interviewer. More often they are talking to each other about what has not been working, what has never worked.

Mrs Balani was married at the age of 15, leaving her family home in India where she was treated like a 'little princess' to migrate to Nairobi and a small household where everybody worked very hard; 'I never had a rest, I'm just working, working, working.' Before his stroke Mr Balani was a workaholic his wife says. He took control of everything in the household, including her. This was his *modus operandi*. His own father had been an alcoholic, Pavita tells me. At the age of 13, Mr Balani had become the family breadwinner, making small toys and trinkets to sell at the roadside and helping his mother to care for his

eight siblings. After his migration to the United Kingdom in 1961, he continued to support his family in Africa, eventually paying for the passage to England of his parents and six of his brothers and sisters.

Even though she had worked full-time in a factory after their migration to the United Kingdom, Mrs Balani had not been allowed to shop for the groceries or to know anything about the household finances. 'Now, it is all upside down' she says about her life after Mr Balani's stroke. At first it was family members who took her out of the home and to do the shopping. More recently it is Chirag, the home carer, who is a new migrant from India.

When the Balanis' lost their home after their small business went into bankruptcy they had gone to live with one of their sons. The arrangement did not work out. Mrs Balani felt as if they were a burden. So the couple moved on to another son's house. Again she felt that they were in the way. Her grandchildren were not used to having their grandparents around. They resented her authority. After a couple of years of moving between her sons, the Balanis moved into a council flat by themselves. Their large social network began to wither away. 'When you are down and out even your family does not want to know you. My family never came into my house – no, perhaps three times in one year.'

Before her father's illness, Pavita says that they were visited almost every weekend by relatives, who looked upon Mr Balani as a paternal figure. Now it is all different 'the relatives have moved away because it's like "Oh it's not fun going down to their house anymore"'. 'They are coming back slowly', Mrs Balani reminds Pavita.

This happens several times during the interview. As difficult stories or emotions begin to surface, Mrs Balani tries to cancel or retrieve them before they do any damage, like a grandmother scooping up a unruly infant. Of the time spent moving between her sons' homes she asks 'Is this a life?' responding quickly to her own question 'We've had a good life, really'. At this stage of her life Mrs Balani says that she will not blame anyone. It has to be 'forgive and forget'. 'You can't demand from anybody, I know this. Love. Love each other. That's it.'

Love is a refrain for Mrs Balani. At times it was seemingly unconnected to the conversation, not requiring context, just needing to be said out loud. Here we had been talking about the difficulties of bathing Mr Balani.

Yasmin: Did you get any support for yourself as a carer?

Mrs B: I love my husband. I can't live without my husband.

Pavita: I think that's her biggest nightmare thinking 'I don't care what he's like.' She dreads the fact of what will happen if she loses her independence completely and has to go and live with somebody.

Intermingling with the hardships and drudgery of caring – Mrs Balani cannot remember when she last had a full night of sleep – there have been new freedoms; a liberating redistribution of familial power that is usually unrecognized in social policy and campaign narratives of family care that pivot on simultaneous tropes of the victimization and romanticization of both carers and disabled people. That illness has been empowering for Mrs Balani by incapacitating her husband, loosening his power and control on family life, is beyond doubt.

For Pavita, the love that Mrs Balani declares for her diminished husband, is most readily acknowledged as a heartfelt valuing and commitment to her own newfound independence. It is a reading that is bittersweet, opening up webs of incapacitation and care across generations of women in the family. A very different rendering of the feminized global care chain. Pavita says that in Africa her mother had always been dominated and ‘repressed’ by her grandmother.

But even then, dad was quite a dominant partner. The reason why she didn’t go out was because she didn’t have a choice, you know. So all this time he was quite a dominant character and ‘You do as I say’ and that was it, you know and all of a sudden now, she takes over the role and it’s a huge personality change for mum, absolutely completely, because I’ve never seen my mum even speak up for herself and that’s why I’m the way I am, because I refused to be like her when I was growing up, thinking ‘I’m not going to be like you. I’m going to be outspoken and ambitious’, because I wasn’t allowed to study as well. At eighteen, I got married, because that’s the norm in our family, you know, the woman aren’t [...] and that’s how mum was treated as well, but as she said, you know, working and everything, but we didn’t know any different, so you just do it and my grandma was like in charge.

This time, Mrs Balani does not add anything to what Pavita has to say. She seems to understand and accept the assertion that illness and infirmity can be beneficial when it is the power of a family despot that is eroded; that illness, disability and care have many different sides and outcomes. It is a testimony to the character of both women that they do not say anything about the delivery of Karma and the fairness of Gods who will ultimately see that you get what you deserve.

As we exchange small talk at the end of the interview Chirag arrives to take Mr Balani for his bath. There is a frisson in the room. Mrs Balani’s eyes light up and she exchanges a joke with Chirag. Mr Balani glowers. As Chirag walks across the room in front of him, Mr Balani slides down slowly in his chair and kicks out at him. The kick misses. Chirag and the women laugh. He will often lash out at Chirag, but that is just his way Pavita says.

Genograms

End of life care in the home is a different type of care giving. Palliative care professionals working in the community tend to see themselves as having a more intimate knowledge of their patients. A consequence of longer-term relationships with dying people and the conditional intimacies of entering into the sacred spaces of the home where people are less institutionalized.

These professionals are shown family photographs and the rising damp in the bedroom. They are introduced to friends, neighbours and the family cat. Many are competent cultural analysts, able to read the meanings and vocabulary of the arrangement of ornaments, photographs and furniture in a home. They often learn something of the hidden economy of herbal pharmacopoeia, hope and magic that connects homes in London and Birmingham to Beijing and Dhaka.

Nothing it seems can be taken-for-granted, so home carers have learned not to presume. They ask whether they should take off their shoes before entering some houses. Sensitive to variations in cultural decorum, they tread carefully.

Figure 11.4 Home furnishings.

Courtesy: Nadia Bettega

Tom, a palliative care social worker in North London describes meeting the family of a dying Rabbi in Golders Green.

The main carer was his wife and I was just very conscious that as a man, I should not shake her hand. But as soon as I got in the door, she grabbed my hand and shook it and then we were really quite careful about how we addressed the Rabbi. She said, 'Oh, forget that, his name is so and so, call him that, that's fine.' Whereas in another household that wouldn't have been fine at all. So it's kind of gently feeling your way into that particular household, with that particular family.

The skills that are required in community palliative care are considerable. Carers are required to work between professional and institutional codes and regulation and the loitering surprises of every possible version of home imaginable: mansions, caravans, bed-sits, residential care homes, prisons. Domestic diversity can mean tea in china cups and the tasting of an array of specially prepared sweetmeats, or entering dilapidated buildings to tend to an anxious alcoholic.

In hospitals, the palliative care team – where there is one – will liaise with GPs. Hospital social workers will try to ensure that welfare benefits are being claimed and that any home help or occupational therapy has been arranged for when a patient is discharged home. Hospice home care teams are multidisciplinary and usually meet together every morning to discuss their patients. Team members will describe new patients to their colleagues and discuss developments and problems within their existing caseload. The level of detail is spectacular and the matter of their business makes home carers local historians with X-ray vision.

Genograms – maps of patient's kinship and personal relationships – are used to introduce new patients to the team. The symbols and codes are extensive. The most basic symbols signify gender (a square for a male, a circle for a female), with other signs denoting a spectrum of relationships: marriage, divorce, separation and co-habitation. Children are drawn in below their parents, ordered from the oldest to the youngest, left to right. Miscarriages, stillborn births and abortions are recognized. There are even symbols for family pets (a diamond).

A glance at a genogram can place the patient's generation and often their cultural background. The genograms of white, British, working-class families are wider and deeper than their middle-class counterparts. Cousins are given prominence in the networks of Caribbean patients and in common with South Asian patients there are an array of aunts and uncles. There is sometimes not enough space to map a full genogram for the connubial relationships of some Caribbean men. Amid such nuances, the commonalities are striking. Racism and resentment of migrants and minorities, especially South Asians, is most readily

associated with the working-class, but the bare bones of a genogram reveals a depth of shared, caring relationships and structures between white working-class and South Asian families.

Working through an array of medical and demographic information, home care meetings are forensic, yet informal. Unrelenting technical jargon and a warts-and-all documenting of the small intimacies of what goes on behind closed doors. At a home care team meeting in a London hospice, I hear about Jim, aged 65, with cancer of the buttock and lung metastases. Jim's nurse, Lydia, tells her colleagues that Jim is becoming disorientated and anxious. He does not want his wife Tracy to leave him alone and becomes agitated even when she visits the toilet. He has demanded that Tracy pees in a bucket in their bedroom. The District Nurse is concerned about Jim's lack of appetite. Jim's son had phoned Lydia in distress, the hospital had told him that Jim has only a month to live. There are tuts of disapproval around the room. I hear a muttered 'outrageous'. The palliative care consultant suggests that the radical surgery on Jim's buttock was unnecessary. Reading the signs, she states matter-of-factly 'He's going to die at home'.

Then there is Jocy from Gibraltar, whose every need seems to be anticipated and met by her two daughters. Jocy has confided in her nurse that her daughters are unable to acknowledge that she is going to die, a situation made more difficult because Jocy has defied her prognosis repeatedly. 'I've been writing "death imminent" for ages and then she rallies' her nurse says, adding 'A lot of it is love that is keeping Jocy going'. When Carole announces 'Pat died yesterday' stillness descends upon the meeting. The sense of loss feels real and personalized. 'Very sad news' says a nurse beside me.

Bernadette introduces a new patient. Shirley, a Barbadian, is 54 with Motor Neurone Disease. She has two children. The youngest, 14-year-old Sebi, is being unusually helpful around the home. The team's social worker comments that it is a classic case of 'If I can be as good as I possibly can, Mummy won't die'.

Eileen McNaulty is 62, with cancer of the cervix. She lives by herself and is visited regularly by a granddaughter. There are concerns about Eileen's financial situation. She is a self-confessed shopoholic. The Citizens's Advice Bureau is helping Eileen to better manage her extensive debt. Eileen's immediate medical problem is her increased incontinence that is reducing her mobility. Eileen's nurse, Viv, comments that if anything, it is the incontinence that will keep Eileen to budget. She makes a note to visit her later on in the day.

The team meeting has taken one hour and five minutes. Thirteen patients have been discussed. Afterwards, team members return to their offices and check the central diary that contains information about the follow-up phone calls and

visits that they need to make that day. They can be on the telephone for the next hour or so, talking to patients, family carers, GPs, occupational therapists and district nurses. Then they take to the road on home visits.

A view

Caring for dying people at home transforms locality and place. The view through a bus window or the car windscreen of a home palliative carer is more paranormal than panoramic. Neighbourhoods are corrugated with loss and peopled by ghosts. As they pass a block of flats, home-carers recall the smiling face of a child who would watch for their arrival. They relive the existential angst of kerbside conversations with family and friends. They know of the small, unseen tragedies that lie behind a home or shop that has come up for sale, the new conjugations between spouses in bereavement groups.

Home visits in cities traverse the infrastructures of biographies, households, cultures and continents. And often in a single street. The social discrepancies between deaths in London are vast. A report by Lord Darzi into health care in London in 2008, depicted socio-economic differences in life expectancy within the capital in stark terms. 'Just eight stops on the Jubilee line takes you from Westminster to Canning Town where life expectancy is seven years lower.'¹⁶ A palliative care community nurse in West London,

We've got lots of people living alone. Single mums with kids, and if they're asylum seekers they might be living away from their children. It's very, very varied here. And then of course you get the old traditional working class families. We still get a few of them, where they've got big families and there's lots of siblings and they all live nearby, but you don't get that very much anymore.

Home deaths for those living alone are the most difficult to achieve, unless there is a reliable network of friends and relatives who are willing to provide 24-hour support towards the end. But sometimes it is the very proximity of loved ones that is the problem.

On a visit to a Gujarati family in Wembley, there are nine members of the immediate household. Only four of them know the prognosis for the grandmother, Mrs Patel, who is semi-comatose and dying. The eldest son had taken the decision early on in his mother's illness not to tell her about her diagnosis. He feels that his mother would have *given up*, the truth hastening her death. As we leave the house, his wife, Meena, follows us out.

Meena tells us that Mrs Patel had asked several times about her diagnosis. As a non-English speaker she had been frightened by the partially explained tests she had had in hospital. The family always acted as her interpreters, filtering and blocking communication between Mrs Patel and health care professionals. Yet Mrs Patel seems to have known that something serious was unfolding in the energetic exchanges around her, that were transporting affects beyond anything that could ever be translated into language. For Meena it is apparent that her mother-in-law had insight into her condition. Shortly before her decline into unconsciousness, Mrs Patel had gathered the family together and distributed her jewellery among them.

The ethics of such family dynamics are gut churning for home carers and they draw heavily upon their skills in cultural diplomacy. They can get caught-up between a focus upon individual rights and autonomy and the need to remain open to more collective ways of being and decision-making. There are also the practical consequences of family conspiracies, regardless of culture, that need to be considered. When a dying person is unaware of their diagnosis, pain and symptoms can be more difficult to monitor and control. Patients can become unduly anxious and fearful. Family care can be more susceptible to breakdown, culminating in the blue-lighting of the dying person into an unfamiliar Accident and Emergency department where they can face a barrage of distressing and futile emergency procedures.

David, a Community Nurse Specialist, feels that there will be some improvement with time as more people talk about death and become aware of palliative care. His greatest challenge is working with generational accretions of culture within the same households.

I remember a very large Muslim family. The younger generations were pushing for more active treatment and perhaps had more understanding about medications and understood decisions that were being made and wanted to take part in those decisions and wanted information. But at the other end of the family line were fiercely orthodox Muslims who said 'It's in god's hands. Nothing to do with us', and didn't really understand the nursing role either. So we were trying to manage all of this in one family, under one roof, and it was really difficult. At the end of the room I could see this patient but I just couldn't get to them. So, I called a family conference in the end to try and get some cards on the table, hear different people and let the family hear their different views, so they could actually understand one another and understand those motivations.

And did that work? I ask.

To an extent, but only for a little while and then they sort of went back into their corners.

Closeness to pain and suffering and to very different ways of dying can take its toll on home carers. In some cases, jangled nerves and insecurity can induce and reinforce crude stereotyping. At other times a stuttering in the taken-for-granted that makes itself felt as friction, foreignness, a murmur of other possibilities, extends routine and thought in a new directions. It brings a *style* to the lexicon of care. 'A style is managing to stammer in one's own language' the philosophers Gilles Deleuze and Claire Parnet have written, 'It is difficult because there has to be a need for such stammering . . . Being like a foreigner in one's own language. Constructing a line of flight.'¹⁷

Carmel speaks with such style in describing some of the difficulties she has encountered with Hindu and Sikh home deaths. But it is not the obstacles that have stayed with her.

There can be a real exquisite sort of peacefulness about their approach to death, something very tender and really wonderful to be around. I think it's about handing things to god and about gaining some peace in terms of how you've lived your life and having some faith in that. It's something that I don't have much experience of, but it's inspiring to be a part of.

A cough

Rachel Gately is part of a district nursing team that operates out of what is not much more than a huddle of portakabins. District nurses provide most of the hands-on health care in home deaths, often seeing patients two or three times a day and fitting this palliative care into a generalist caseload that can include routines of wound-dressing, continence care and taking blood and urine samples. Rachel is accustomed to being a social and technical chameleon, adept at multi-tasking. She can eat, write-up notes and make phone-calls simultaneously. Rachel tells me that it is the unpredictability of her work that is especially stressful. Dying in localities has its own temporal rhythms, and death it seems can come in waves. Rachel's caseload can be palliative care free and then there can be up to six or eight dying people in the team's patch. At such times it is her other patients who can pay the price in more fleeting and trimmed-back visits.

Rachel's boss, Christine, has just returned to the office after trying to sort out the delivery of a hoist to a high-rise flat on a notoriously rough council estate in

South East London. The matriarch of a long-established, white, English family is dying. What should have been a routine delivery became fraught. Tempers flared and threats of violence ensued. The hoist would not fit into the one lift that was still working in the tower block. Health and Safety regulations prevented the delivery personnel from carrying the hoist up five flights of steep stairs. In the end the Health and Safety regulations were forgotten. The family enlisted the help of neighbours and together they carried the hoist up the stairs.

Rachel has spent most of the afternoon on the phone, tracking down a specialist, pressure-relieving mattress for a double bed. The mattress is for an elderly couple, originally from Jamaica. The husband has prostate cancer that has spread all over his body. He is not a talker, keeping his feelings and anxieties to himself. He comes from an era where stoicism and fortitude are the trademarks of manliness. As Edgar in *King Lear* put it 'Men must endure'. Rachel's assessment of the domestic situation is incisive.

He knows he's dying and she knows he's dying, but they can't actually verbalize it together and he's keeping himself awake at night coughing, coughing and coughing. He keeps denying he's got pain, but you can see from his expressions that he's got physical as well as an awful lot of emotional pain.

Rachel had suggested medication to help her patient sleep. He had refused the sleeping tablets 'in case of a fire'. Reading between the lines, Rachel says,

And his biggest fear is that if you give him something to help him sleep he won't wake up again and he'll die. So I think the cough is his way of trying to keep himself awake because he's afraid he'll die in his sleep. They have a very strong faith which I think is what's helping them through the whole time and the priest comes and he seems to be the one that's pulling them together and forging that bond. My staff nurse had seen him first and had ordered a highfaluting pressure mattress. So I went to see them and said 'My colleague has ordered this for you, where do you normally sleep?' And the wife said 'Well, we've slept in the same bed for forty-three years'. And I said 'Well how will you manage if we put your husband in a single bed?' 'Oh I'll sleep in a camp bed next to him.' I said 'Well at the moment things seem to be OK. If I get a double mattress would that be more preferable?' And that was what she wanted and that's what we've done.

I think we will probably need to get a hospital bed and a super-duper mattress another two weeks down the line, but we've given them another three or four weeks of sleeping next to each other in bed, which I think is much more important for the moment while they build up their trust of us and cope with the loss of each other.

How to place a value on this mattress and the three to four extra weeks of sleeping together that Rachel brought to this couple? It will not be apparent in any accounting sheets or in audits, the medical case notes or even to Rachel's colleagues. There is a beauty to this poetic realism in care: unquantifiable, life and death changing and most often invisible. These rare places of sojourn for the combatants of reason and affect are as much a part of the richness of ordinary lives as they are the stuff of literary symbolism. In the Henry James novel *The Europeans*,¹⁸ brother and sister, Felix and Eugenia, discuss the prospect of Felix's marriage. Eugenia muses that if Felix is as reasonable a husband as he has been a brother, his wife would have little to complain about.

'Felix looked at her a moment, smiling. "I hope," he said, "not to be thrown back on my reason."

"It is very true," Eugenia rejoined "that one's reason is dismally flat. It's a bed with the mattress removed."

What I learn from listening to Rachel and to other home care professionals is that care for stay-at-home patients can be deeply felt. It is without doubt a world of daily compromises, staff shortages and ongoing cost-cutting. And then in the midst of the everyday routines and frustrations there is also a world in which a mattress can extend love's time.