"What Happened to You?"

WRITING BY DISABLED WOMEN

EDITED BY LOIS KEITH

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To Colin, for helping to make things possible
Molly Holden

'Along the lane . . .' 

Along the lane go two of almost equal height, her arm through his. She takes my place, so sweet a surrogate no harm enters my mind. Yet I can hardly bear to watch my daughter on her father's arm. Salt in the wound. Fate gives no quarter.

Lois Keith

This Week I’ve Been Rushed Off My Wheels . . .

Some weeks come together and some are full of separate days. This is a seven stories week.

On Monday I had a puncture. Amazingly the first in nearly eight years. Monday and Tuesday are my school days. I teach English in a big comprehensive in the middle of London. 10P were listening, unusually rapt, as I read Rosa Guy's novel The Friends.

‘Oh look, Miss,’ said Akbar suddenly, holding a drawing pin in the air, ‘I’ve just pulled this out of your tyre, shall I put it back again?’ (He did. Two punctures instead of one.) He held it for me to see. We all looked up. ‘Oh, Miss’, said Mitchell, ‘I can hear your tyre going down.’ He made the noise through his teeth - ssss.

‘Don’t be silly,’ I said, and we read on as beautiful Ramona rips her dress down to the waist to reveal to her shocked children and husband the scars where her breast had been. ‘Calvin,’ she says, ‘they must take this lesson from us. This lesson of how life twists us so that we put value on worthless things. Puts beauty before you to blind you to what beauty really is.’ The class were stunned (it’s not often they get naked bodies on a Monday morning), while I wondered if pushing like that was possible, imagining myself in a heap in the corridor in front of all the kids. My tyres and I both sighed. Ahh.

In the office I was definitely shaky. My colleagues were sur-
prised and made me cups of tea. Inside I felt stranded like a frail raft at sea.

At lunchtime I sat in my car whilst Peter from the Physics Department mended my tyre with his puncture kit. Ellie, Head of Special Needs, was keen to have a go. 'That's brilliant,' she said. 'I've always wanted to know how to do this. It'll be really useful when I do the London to Brighton Friends of the Earth Bike Ride this Saturday.'

I rang Colin. He worried and came home early with a bunch of flowers. I rang Jenny. She laughed and said 'God, how awful,' and told me how that morning her lift had broken and how she'd had to bump herself down forty-three steps to make the breakfast.

I went to bed early remembering how it had felt wheeling through the empty corridors leaning to the left, insecure and unbalanced. I hadn't fallen. I hadn't made a fool of myself. Everything was all right. I fell asleep thinking how fragile it is, my grasp of independence.

On Tuesday I forgot all about it. 10P and I read more of The Friends and learned from Rosa Guy how hard it is to be a young, black fifteen-year-old girl growing up in Harlem and how bad it feels to betray your best friend. At half past four I left school, my teaching days done — until Sunday when I would spend the evening marking and preparing.

At six o'clock I hit the road again. I was in an optimistic mood. Nervous though. I'm always nervous about going somewhere new. This anxiety is rarely a social one, it isn't about meeting new people or feeling shy. I had thirty-five standing up years to deal with that one. This 'normal' anxiety is displaced for me by the sheer physical concern of going to a place I haven't been before. Of finding a place to park, worrying about whether I can get out of the car straight on to the pavement, whether there will be kerbs. It's anxiety about asking a total stranger (if there is a total stranger to ask) to help me in some way. It's the fear that there will be some obstacle no one has told me about — a step, a bollard, a pothole, a locked door.

But tonight I felt sure it would be okay. The guy on the phone had sounded so knowing and helpful. I'd told him exactly what I needed, I'd made it crystal clear. He said he'd sort it out, someone would be there to help, he'd be at the meeting himself. He hadn't called me back as he said he would, but was it likely that a theatre company for disabled people would organise a workshop for disabled writers in a place inaccessible for wheel-chair users? Of course not.

I'd left home early. The map they'd sent me was unreadable but I'd written down the address when I'd spoken to him on the phone. Interchange Studios, Wilkin Street. I found it, although it certainly wasn't easy. A gloomy, between the railway lines sort of place. Glum housing estates, poor lighting, cul de sacs, no man's land. Certainly no woman's land, I thought, seeing a solitary female wandering down the dark alley, searching like me, I learned later, for our workshop.

I had driven down a long, narrow drive signposted Interchange Studios. At the end there was no parking, no visible entrance, no way to get in. I telephoned from the car (lucky me to have such equipment). No answer. I sat in the dark for five minutes willing someone to appear and show me how to get in. It was then I saw it, a little sign just inside my vision. Entrance to Interchange Studios has now moved to Danby Street. Where the hell was Danby Street?

It was now six-twenty. I looked it up in the A to Z. This area had more roads per square inch than any other part of London. I reversed all the way up the lane, my idea of a nightmare, back to the main road. No right turn, dead ends, three point turns, reversing round corners, until I finally found, emblazoned in lights: Interchange Studios.

Completely inaccessible. A dark, rainy night, nowhere to park, no way to get in. Huge bollards, an unbelievably steep and cambered concrete slope, chicken wire fence and no one there. I telephoned again. From the car I could see lights on, lots of people in the building. No reply. 'Don't cry,' I said to myself firmly. 'Don't cry, you're not to cry.' It never works.

By this time I was late and I was angry. Then two young
women passed, black jeans and long hair, carrying musical instruments. ‘Excuse me,’ I called out. I didn’t want to have this conversation. To talk to strangers you have to be pleasant and jolly and that wasn’t how I felt. They stopped, looked at me, looked suspicious. I didn’t want to have to say this. ‘I’m disabled, I use a wheelchair and I can’t get into the building. I wonder if you would mind seeing if there’s someone from the writing workshop in there and ask them to come out and see me.’ Out came the man from reception, bearded, smiling, not unfriendly. I asked him to find someone from this workshop to talk to me. I was wound up like a top. I just wanted to say my piece and go. I wanted to be at home.

‘This is what the world does to us,’ I said to the young woman who appeared. ‘We shouldn’t do this to each other. How dare they organise something for disabled people in a venue like this and not tell anyone about it? How dare they think that’s okay? There’s no one here to meet me, no one answers the phone. I’ve let other people down to even come here. I should have been somewhere else but I wanted to come. I ring up, I ask all the right questions. I get here and I can’t get in the fucking building.’ And then I cried.

Unusually, she listened and wasn’t defensive. She didn’t tell me that I was over-reacting or that it wasn’t her fault. She said, ‘It’s awful, it’s awful. Can I give you a hug?’

‘No you can’t.’ This was my rage and I didn’t want to share it.

‘No one told me. Why didn’t they give you my phone number? It shouldn’t have happened. I’m so sorry, I’ve had a bloody awful day myself.’ And then she burst into tears and we were both crying.

‘Oh God,’ I thought, dismayed at her tears, pleased she wasn’t accusing me. ‘Come on,’ I said crying, laughing, supporting her now, ‘I might as well go in, I’ve come this far.’

So together we negotiated the awful ramp, backwards so I didn’t fall out, whilst she explained to me that this was temporary and soon there would be a proper car-park with proper spaces for disabled drivers. We went through endless corridors with chipboard room dividers and sinks with noticeboards, until we reached the room where eight people were sitting round a table with their eyes closed and a woman with a round face and brown wavy hair was saying softly, ‘I want you to imagine you have something in your hands – some very special possession which only you have. I want you to think about its shape, its special smell, its feelings, and when you have it all clear in your mind I want you to write it down.

So I wrote:

My anger has no shape.
It’s fierce, it hurts,
it’s futile.
I want to aim it at the person sitting at this table who deserves it.
Let him eat it,
let him keep its bitterness.

After that I began to feel better and when it came to my turn I read it out. ‘Mmm,’ said our workshop leader, ‘thank you,’ and with her mouth slightly twisted, moved quickly on.

Wednesday was a day for me.

In the morning Rachel and Miriam got themselves ready for school and, sensing somehow that I was not entirely with them, made me tea ‘in the cup or in the pot?’ and a crumpet with jam. Not that we don’t fight, we do. But not this morning, for which I was very grateful. Our fights are the sort of fights that all strong mothers have with strong daughters, I think. I get more than averagely irritable with them when they leave their things on the floor so that I can’t get around and I’m not always good enough at hiding my raw feelings from them. I don’t want them to feel they have to worry about me.

People used to say that they were like a little one and a big one of the same thing but now they are growing to be very different. Rachel is eleven, tall and slim and, as her grandfather put it, getting a shape. She is loving and thoughtful, funny and complicated, and is going through a difficult phase which looks
like it's going to last until she's at least thirty. Miriam, who is nearly nine, is rounder, sunny natured and affectionate. She is learning to be difficult but it doesn't come easily to her. She adores her big sister who loves her back, even when they fight, which is mercifully rare.

Rachel was three and Miriam just two weeks past her first birthday when I was run over by a speeding driver in Australia. My separation from them, my inability to be their mother, was more painful than knowing I would never walk again. People who do not live with a disability find this impossible to understand. Now I try to be a strong enough mother to them, and mostly I succeed. They understand more than other children about fairness and justice and why disabled people have to be fighters. They don't like the way people stare at us when we're out together and have an acute awareness of when people are being patronising. When someone passes the three of us going about our business in the supermarket or the shopping centre and smiles in a sickening way muttering 'How sweet', or asks me (or them) if I'd mind telling them how I came to be in a wheelchair, we imagine replying, 'It's a disease that strikes people who say stupid things.' We don't, of course.

I like being out with my children and I know that it's not just because I like their company, which is a good reason, but because it normalises me in the eyes of the public, which is not. They're still not too old to want to climb on my lap and have 'taxi rides' to bed. I don't want them to grow up too quickly. It will be hard to let them go.

It is bliss to have a whole day to work, muse and reflect, until three-thirty that is. I want it both ways. Within the loving cocoon of my family, I need time to be by myself. When I first started writing after my accident it was to save myself from the kind of despair I didn't know was possible. One of the first things I wrote about was the idea that I would never be alone again, that I would never be able to wander about or sit in a cafe eating something delicious, reading a book with no one knowing where I was. A year or two later when I rediscovered the trick of being alone, it felt wonderful.

So today, after I took the children to school, I came home, made myself a pot of good coffee and took it into the Room Of My Own. Well nearly. It does have the computer in it which the entire family wants to share, but it is still called 'Mummy's Room'. I was more fortunate than many; the courts ruled that my paraplegia was someone else's fault and I received compensation. Together Colin and I built a beautiful, light house in the middle of London and in it I have this funny triangular 'wedge', which Rachel called the 'Brie Shaped Room' when she first saw it. It has a wooden floor and a beige and blue Persian rug which belonged to my brother. I have what Alice Walker describes as a most desirable feature in a working room, a view of the garden, and it is full of bright pictures and postcards. Today is a day for me.

On Thursday I went for lunch with my friend Sally. We met after my accident. Sometimes I classify things like that, before or after. Increasingly these days it doesn't seem important.

I met Sally at playgroup. I found it hard in those early days to socialise with all the mums each morning and one day I rather guiltily asked three-year-old Miriam if she'd made any friends. She said she had a friend called Thomas. Later I learned that of the twenty-four children in Highbury Playgroup, four were called Thomas, so it was quite possible I'd cornered the wrong mum. Still, it didn't matter because Sally and I liked each other.

Sally thinks I'm AMAZING. This gets in the way of our friendship because although sometimes I am amazing, I am never AMAZING. When we're out together I make her nervous. I don't want to but I do. Negotiating the kerbs of busy Upper Street on another wet afternoon, she hovered over me, unable to accept that I would tell her when I needed help. It reminded me rather of learning how to quickstep at the Arthur Murray School of Dancing with my brother when I was eleven. We both wanted to make the moves, and we were getting in each other's way. Still, Sally is my friend and she's clever and funny so I try not to let it matter.

After our meal I was getting into my car when the all-too-
familiar happened. In a busy road, with cars parked on both sides, I kept the traffic waiting whilst I folded my wheelchair into the nifty mechanical hoist which stacks it on the roof of my car. A thirty-something, City banker, BMW type approached, offering much-unneeded help, and tried to close the door, which clearly wouldn’t shut what with the hoist very slowly moving its way up.

I was pleased with the way I dealt with this one, uttering a pithy phrase like ‘Leave my door alone, you stupid idiot, can’t you see you’ll just have to wait’ and at the exact moment, slamming the door shut. Furious, his face now scarlet, he swore at me through the closed window, insisting he was only trying to be helpful.

What can you expect? I turned to Sally, expecting solidarity, sympathy. Hadn’t I for once been AMAZING, dealing so adeptly with one of the pillocks of this world? Silence. Sally did not approve. She was upset and thought I had been unfair. She wasn’t proud of me.

We began to talk about the unspoken layers of difference between us. Her dislike of aggression, my feeling that it is sometimes the only way I can deal with the world. Her feeling that in rejecting genuine help, I was rejecting her. My feeling that she had to accept my definition and understanding of the world. I lived it. I knew how thinly people disguised their patronage, fear and dislike of people who were different, people who were disabled. Her feeling that there was more rage here than she could deal with. We both cried. We made up. I respect her for wanting to talk about it honestly, but it hurt us both.

Later there was Colin to tell it all to. We may disagree and argue about everything, from who said they’d buy the butter on the way home from work to who does the most loving and supporting in this relationship, but on this we never disagree. My definition of the world as a disabled person has become his. If I come home from work telling him how everyone stood in the lift looking at me and none of my colleagues would move so that I was five minutes late for my lesson, he never asks me to look at it from their point of view. My anger is his anger. Miraculously, I am the same person for him as he is for me.

On Friday. The Weekend Starts Here, as they used to say on Ready Steady Go, but this Friday, I have to say, was a killer. The day was fine. I prepared for the Women’s Day on Saturday, took the children to their dance class, made supper for them and the babysitter, and then we went to the cinema. I’d rung up; booked the tickets, told them I needed an aisle seat, told them why. This cinema, arty and modern, has lots of stairs but great films. Colin’s good at this type of thing, we lived for a year in a house with three floors.

Outside it was raining – it’s been raining all week. Inside it was packed with the kind of audience who respond to good reviews in the Guardian and Time Out. We collected our tickets from the box office and, moving through the crowd, Colin began to bump me down the long flight of stairs, like Christopher Robin with Winnie the Pooh only forwards. Near the top we were stopped by a man with a black pony-tail and the sleeves of his jacket rolled up so you could see the silk lining. The conversation went something like this:

Him: Are you going downstairs?
Us: Yes.
Him: (To Colin) Can she get out and walk?
Us: No.
Him: Well you can’t take that wheelchair downstairs. It’s against the Fire Regulations.
Colin: (It’s hard for me to talk at an angle of forty-five degrees – bump, bump, bump.) We’ve bought our tickets and we’ve been here several times before.
Him: Well, they shouldn’t have sold them to you, I can’t let you in.
Colin: This is ridiculous, it’s fascism. It’s like telling someone they can’t come in because they’re black.

By this time we were halfway down, turning the corner to the second flight. Managers in trendy cinemas in Camden get very
edgy when you mention racism. They don’t think of disability like that.

Him: It’s not my fault. I don’t make the rules. I’m sorry but I can’t let you in, it’s not safe, there might be a fire.

Colin: Do you ask everyone for a Health Certificate before you let them in, then? No entry if you’ve had a triple bypass? I can carry my wife out in two minutes.

By this time we were at the bottom of the stairs. Finally I could speak, on the level.

I’m going to get into my seat and watch this film. You can call the police if you want to but they’ll have to physically remove me and I’ll scream.

I don’t know where these words came from, I surprised myself. It was as if I’d had them sitting in my head all this time waiting for the right moment.

The film told the story of a poor Indian girl wrenched from her mother into a life of prostitution. I cried for us both. Still, between me and unbearable sadness is a box of Terry’s Neapolitan chocolates. I ate the lot.

After the film the nice usher told us he was very sorry about what had happened and that it would be better to come on an afternoon in the week than an evening at the weekend. This, of course, ignores the fact that I look after my children and go out to work, and so does the person who gets me into inaccessible cinemas. It’s also hard to understand how you can be a health and safety hazard on a Friday night but not on a Tuesday afternoon, or why you’re not allowed in a cinema with stairs in Camden but you’re all right half a mile away in Westminster. Anyway, they won. I’ll never go back.

Afterwards we went as arranged to have a drink with some friends who hadn’t been able to get a babysitter. We’d all been to this cinema a month or two before. They were shocked by what we told them, shocked at my distress.

They listened and tried to see themselves in my place. You go to a movie and you have tickets but they say you can’t come in. They try to throw you out and they have the law on their side. We all had another drink.

Saturday was the Annual Women’s Day held at the Spinal Injuries Unit at Stanmore. Twenty-one of us, women of all ages, from all backgrounds, all four feet high, came together as we have done for five years, some straight from the wards. Joanna, Lynn and I have organised this every year with help from the staff at the hospital.

It felt good to be there. Old friends tried rather unsuccessfully to hug, wheelchairs clashing. New people met more shyly. All day we talked, ate, painted plates, listened to speakers, had make-up put on, looked at books. We laughed about the kind of things we talk about together, recognising that although we may not have met before, none of us are strangers.

Indwelling, intermittent, firing off, evacuation, pressure marks, attitude, access is our shared vocabulary. But so is men, women, love, sex, children, friends, houses, food, music and work.

I went home tired. It had been a good day.

On Sunday I stayed at home. Colin and I read the papers, relaxed and didn’t get up till late. Rachel tore herself away from the television after only a few hints and brought us tea in bed. The children came in for hugs and wanted to play ‘The Game of Life’. We refused and stayed in bed some more.

Getting ready for the day was the difficult part. It always seems like hard work and somehow today, with all that time in front of me, it seemed even harder. 1 Transfer out of bed. 2 Transfer from wheelchair to shower seat. 3 Have shower and wash hair. And so on. Back on the bed I roll from side to side putting on knickers, then tights, then skirt, then shoes. On extreme days I give myself a number of rolls to aim for.

These days I dress in a kind of uniform which suits my needs. Black or navy fine wool skirt, sometimes patterned. Black or navy opaque tights. Dark polo-neck cotton top or shirt. Sometimes a bit of colour in a jumper or a scarf. Often a necklace,
always earrings. Turning forty-three this year, I bought myself my first lip brush and some bright red lipstick. I'm not sure what this means exactly.

If I had one wish it would be to make a spell each morning and appear fully washed and dressed in my wheelchair. I never wish that I could walk again. That's not to say it doesn't hurt sometimes. Usually it's things that are out of the ordinary of my daily life, like a friend recounting the wonderful holiday he's just spent trekking in the Peak District with his family or watching my children with their father exploring the Tomb of the Kings whilst I sit looking down at them. But to wish that I could walk again would be wanting to turn myself into something so completely different that I wouldn't know who I was any more. Like wishing I was a man or wishing I was Japanese.

My wishes are smaller, and increasingly these days to do with vanity, like wishing I had thick curly hair. Or wishing that I was thinner, something which should be in my control but never is, quite. Or wishing that I could wear narrow beige linen dresses. But really I am who I am and these days, that's the person I'm comfortable with.

This Sunday I didn't much fancy cooking and as a treat for lunch we ate smoked salmon beigels with cream cheese and New Green cucumbers. In the afternoon, I got on my scooter and went for a ride to Highbury Fields with the children on their bikes. Colin stayed at home and listened to 'his music' which none of us can stand.

By the evening, I had abandoned any idea that I might work and tried not to think about the consequences for tomorrow. I lay on the sofa and watched television instead. All week I had been at odds with life and now I still felt unsettled.

But that night I slept like a baby.

Anna Sullivan

Summer Poetry

Summer poetry is what you called my writing. Funny, I never thought of it like that.

So was all the grief and pain of my Winter poetry just a seasonal emotion?

Is what I write now just full of sun And azure skies to sleep under?

I think you may find a few shadows Lurking around the patio.

But then you didn't really mean that, did you?

Once a month we meet now instead of every day, And you smile and give me herbal tea To drink and say how well I look and I smile Back, then we talk about music and My diet and share a joke then we Both look at our diaries and I leave.

But I have so many more things To say to you, that I cannot, because You have absorbed my grief for so long Now, that to give you more would show In your eyes every time that you Look at me, so it lies hidden in my Summer poetry skulking beneath The deckchairs and shimmering heat.