

LESLEY ANNE SELLWOOD
(1944 – 2009)

My sister Lesley was born when I was 3½ and living in north London. Our mother knew immediately that there was something wrong with her baby but no medical professional was prepared to enlighten her. After some months, and concerned about the shape of her baby's eyes, she managed to persuade her GP to refer her to Great Ormond Street Hospital. There she learned for the first time that Lesley had Down's Syndrome and nothing could be done to alter her appearance.

A third girl was born in 1946, three months before Lesley's second birthday. Lesley's development was slow and she was very wilful which meant considerable strain for our mother. If she didn't want to cross the road, for example, she would sit down in the middle while her mother tried to get her to her feet as well as manoeuvre a pram safely and avoid passing traffic. I recall another scary incident. Nappies were drying on a clothes horse in front of the living room fire. Lesley decided to take them down and throw them on the flames. Our mother managed to rescue the situation before the need to involve the fire brigade. That would have been especially embarrassing as our father was serving in the Auxiliary Fire Service.

Our mother had been an only child and was hoping to have a large family herself. She was obviously struggling and was persuaded by her husband and the GP that it would be a good idea if Lesley were sent away for six months' respite. She went to a retired nurse in Bristol who found it very difficult to cope with Lesley. Her parents were not allowed to visit, such was the wisdom of the time, and it is hardly surprising that Lesley didn't settle there. After this experiment, the decision was made that she should go away permanently. Responsibility for her upbringing was transferred from her parents to Haringey Council. For the next thirty-odd years she was in the care of Harperbury Hospital, one of the major institutions for people with mental health problems.

Lesley learned to read and write, achieving the standard expected of an eight-year-old, and flourished in their care. Her interests were knitting and rug making. Above all she was incredibly proud of her 'large family'. It always surprised me that she should have such strong feelings for a family which she could have no recollection of having lived with. As her siblings married and had children, she would remember all their names and to which couple each child belonged. Our parents would visit, taking her out to St Albans to have tea and to shop for new clothes. Once I had passed my driving test, I would drive my mother there and was amazed by the standard of the Nativity play and Carol Concert I witnessed on one such visit.

Our father had never been able to come to terms with having a child who was not perfect. Only people who were around at the time of her birth knew of Lesley's existence. This included keeping her siblings in the dark. It was explained to me that no one needed to know about her, she was unlikely to live beyond her early teens, and in any case other people wouldn't understand. I hated not being able to talk about her to my friends and family. By the time antibiotics were changing the probability of living longer, my father decided his other children should be told about Lesley as they reached their majority. Each of them reacted somewhat differently. My sister was the first to know and the news

was broken just as she was to start her nursing training. She greeted the revelation with some anger as she would have liked to have got to know this missing member of the family. She was taken to meet Lesley almost immediately and was saddened by being unable to feel any kindred spirit. Lesley didn't look like anyone else in the family and she couldn't summon up any love for her at that time. A couple of years later our two brothers were let into the secret about the same time as each other. The elder one was about to leave the country on a gap year and decided, since he hadn't known anything about her before that, it could stay that way and had no interest in meeting her at all. The younger was about to start his medical training. He became interested in how Down's Syndrome came about and we learned a lot about chromosomes from him. He lived a good distance from London but we arranged to meet up with Lesley on a few occasions.

Had it not been for the government's decision to empty the institutions in favour of "care in the community", I guess Lesley would have ended her days at Harperbury. As it was, she was one of the first to leave. She and three others spent a year in a house in the grounds, learning what it means to be independent. She learned to handle money, shop and account for the change, to undertake basic cooking skills, clothes washing and house cleaning as well as personal care. At the end of the year, she and her fellow residents were discharged into a hostel, with on site carers. She spent nine years there, having her own room for which she had total responsibility, with a key so it could be kept locked when she was not in. She had a part-time job at Remploy and attended Church regularly. The local community were very supportive and would turn up for birthdays or other celebrations. My sister and I would visit with our children, taking her out for walks in the park. Everyone we met would be told, "This is my sister" and "Aren't I clever?" She was obviously very proud of us. With hindsight, residence in the hostel was an ideal arrangement under which Lesley thrived.

Pressure was coming for clearing the institutions. Lesley and three others were moved on, under the care of HAIL (Haringey Association for Independent Living). She shared a house with Carol and two men, Keith and Andrew. It wasn't long before Lesley transferred her affections from Keith to Andrew, who had hitherto been Carol's boyfriend. Fights ensued and the authorities had to make other arrangements. A flat was found in a former almshouse for Lesley and Andrew (who also had Down's syndrome) to live together. They had a living room and kitchen on the ground floor and a bedroom and bathroom upstairs. Lesley soon fell out with the woman living next door whom she accused of having designs on Andrew. She also took against any of HAIL's female carers, insisting that she could look after Andrew. Not only did she decide not to go to work or to Church, she insisted Andrew "retire" too.

Where she learned that word, we don't know, but the purpose was to ensure Andrew stay with her all day. They were responsible for paying their utility bills and for doing their own shopping. HAIL workers were unable to get in to see how they were getting on as the pair refused to open the door to them. Should the carer telephone before visiting to ensure they were there, they would immediately go out. They decided not to pay the bills, switching off the boiler and putting the telephone in a cupboard.

When my husband and I called to collect them for a pre-arranged visit to our own home, we found the house cold. Lesley would proudly show off the fridge contents – all

tomatoes – and the wall cupboard containing nothing but tins of tomatoes. They had taken to going out for meals and were regular customers at British Home Stores where the restaurant manageress allowed them to linger all day. We'd put the boiler on for them but it would be switched off again as soon as they returned.

They had prodigious appetites and could demolish a whole large dish of home-made lasagne and several servings of apple crumble and custard. The rest of the time Lesley would bring out the contents of her handbag for us to admire. Every letter or card which had been sent to her, many photographs of the family and her current knitting project – yet another multi-coloured scarf for Andrew – would be presented for our admiration. Every delaying tactic was employed when it was time for us to get them back home.

I would report back to HAIL who would redouble their efforts to help them, though Lesley and Andrew were supposed to be living independently. One winter's night I received a telephone call from a concerned member of the public. Lesley was out in bad weather without a coat, was in a poor state of health and not keeping herself clean. My husband and I set off across London to see what we could do to help. Their house was in darkness and, though we had a feeling they were inside, no one would answer the doorbell. I rang HAIL in the morning. They were both taken to see the doctor who prescribed antibiotics for Lesley's chest infection, anti-inflammatory tablets for her knees and thyroxine (which she was supposed to take all the time). Andrew's epilepsy medication was renewed as well. Lesley wouldn't take her medication or let Andrew take his.

In 1995, Andrew complained to the carer that he could no longer look after Lesley, who was reliant upon him to do everything for her, and said he wanted to live on his own. A bed-sitting room on the first floor of a house about a mile away was found for him. Lesley was distraught and within a few days had moved in with Andrew! Andrew needed to go into hospital for a minor operation. The hospital had to find a bed for Lesley to stay next to him, as she couldn't bear to be parted from him.

Lesley's weight had soared and her mobility worsened. She had a walking frame to help her but it was obviously not ideal for them to be sharing a room to reach which there were stairs outside and inside the house. In 1999 HAIL found them a brand new ground floor flat with a walk-in shower, fully fitted kitchen and bedroom. Any couple would have been delighted to have such a lovely home. Lesley's mobility continued to be a problem and one evening she fell. Andrew was unable to get her to her feet and the following day she was admitted to hospital with a suspected fractured kneecap. That turned out to be less serious but once it came time for her to be discharged, the hospital would not allow her to be returned to the flat with only Andrew to care for her. She was sent to a respite care home some miles away where she was inconsolable not to have Andrew with her. He would take two buses each way every day to go and visit her but again when he left she would sob. She refused to eat anything but white bread tomato sandwiches. On the plus side, she lost a lot of weight.

Eventually HAIL found a care home where they could be together while they searched for a house where they could have live-in carers. In 2002 Korean and Japanese students were offered their own bedrooms in a house which had been fitted with a stair

lift and walk-in shower. In return they were responsible for looking after Lesley and Andrew's every need. A stretch limo was hired for Lesley and Andrew to go into town for her birthday. Another treat was a short cruise in the English Channel for which she dressed appropriately in evening clothes. Her happiness shone out in the official photo.

The last time she came on a visit to our house, at Christmas 2004, she wouldn't speak at all, indicating to Andrew that he should reply for her. She didn't appear to enjoy the visit and screamed in pain when my husband tried to lift her into the car for the return journey. I was in touch with her social worker who also commented to me that she had started ignoring everyone, even including Andrew.

The house-sharing arrangement worked well for three years until one day, in March 2005, when Lesley was left on the toilet for an hour. When they tried to lift her, her skin tore (it was fragile from pressure sores due to her being wheelchair-bound). She was admitted to North Middlesex hospital where she remained for some months. Her social worker would visit and one one such occasion the consultant was doing his rounds. She seized the opportunity to ask him if he thought Lesley was suffering from dementia. He had some tests carried out which confirmed her fears.

When it came time for her to be discharged, it was to a nursing home in Highgate. Within days she was back in hospital – this time to the Whittington – where she was on antibiotics via intravenous drip for pneumonia. She rallied and was returned to the nursing home. Andrew was still visiting her for some months until even he was no longer recognised. I found Lesley totally oblivious to her situation and it was up to the nurses to do everything for her. She never wore her false teeth so was fed purees. She was doubly incontinent and constantly succumbing to chest infections and urinary infections, always being treated with antibiotics. Her quality of life having deteriorated to zero, we asked that the GP be involved in drawing up an end-of-life plan with the home and the family. Shortly afterwards the next chest infection became her last.

Lesley had enjoyed most of her 64 years. Andrew, her partner for over twenty of those years, came to her funeral and I was told by his carer that he too now had dementia. Our mother, who had long battled with her conscience over not having had Lesley brought up with the rest of the family, wistfully summed up her life with the words, "I could never have found an Andrew for her."

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