Meg's story

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A story in two parts: in 1994 I wrote describing the background of my sister with Down syndrome and the way in which she and I had coped with her care after the death of our mother. I hoped that our experience would be useful to parents facing the prospect of their handicapped child being left without parents. The second part describes the present situation and includes our plans for the future.

Part I: 1994

Margaret Judith Hooper was born 6 May 1946, when our mother was 36. Meg was the fifth and last child in the family. We older children were all born before the war. I think that Meg would have been assessed as having a fairly high IQ for a person with Down syndrome. How accurately indicative that was I have no idea.

Meg was among the first children to be educated by the (then) Sub Normal Children's Association, first at our home, 170 Old Cleveland Road Coorparoo and later at Bowen House. At age 15, as was the system, she underwent prevocational training at Bowen House; I remember hearing about the flat there. She made morning teas and Christmas cakes and learnt other life skills. Making up orders of fruit and vegetables from produce bought at the markets was another activity. This gave her experience in handling money, a skill I notice Meg has lost now.

At age 18 she started at the sheltered workshop at Coorparoo, and recently moved with the workshop to Yeerongpilly.

Our mother died in 1988. It might be useful to describe Meg's skills at that time.

Our mother taught Meg to iron at an early age. For as long as I can remember she always washed and ironed at home for my mother and herself. She also took in ironing for neighbours.

She routinely made her own lunch for work. This was done methodically and neatly. She was not interested in cooking (though she has always loved food and is grossly overweight), but was quite capable of making my mother cups of tea, and of making a light dinner for them both occasionally. She kept her own room quite tidy, making her bed every day, even at weekends.

She had few friends. Some women friends of my mother's were very nice to her, always turned up with birthday and Christmas presents, but it was all one way, Meg did not reciprocate. That would have been done by my mother. She loved to join in family celebrations, and always kept a birthday book. She knew when family birthdays came around, though Mother would be the one who rang to say happy birthday. I remember her 21st birthday, a little dinner party, Meg made a very nice speech. (She is now planning her 50th birthday party!)

She was not keen on holidays, went away only if Mother took her, and did not seem to get particular pleasure from whatever it was. She came away with my family on very rare occasions. In 1988 my mother and I went to the US and Meg stayed at home, but I forget what arrangements we made for her care. My sister Marie lived opposite so she probably supervised. When my mother went away overnight, Meg stayed at home alone, and was happy to do so.

With the encouragement of Mrs McConnell (Principal at Bowen House), Meg learnt to use public transport at a fairly early age. I remember Mother having qualms about it, but there were few problems. Meg has a good sense of direction and sometimes when out with me she obviously knows better than the driver.

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She attended monthly socials at the YWCA and Saturday bus trips. Mother would drive her or organise transport to and from the city on these occasions.

So while Mother lived, it was Mother's life, Mother's home, and Meg was very much an appendage, she just went along with everything and was looked after. But Meg has always been a very caring, sympathetic and completely unselfish person, to the extent that she was an example to the rest of us.

I know our mother expected that, when she died, Marie or I would take Meg to live with us in a specially built granny flat. Both husbands were agreeable. However, on the night of the funeral, a cousin turned up with her nightie and said she

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would like to stay with Meg for a few days. Other help materialised. Before long Meg then took charge herself, drew up a roster, and wrote down a person's name for each night – these included my cousin, a sister-in-law and a number of nieces and nephews. (I have to say that this roster took a bit of supervision. Meg could be a bit dictatorial and nominate nights, rather than ask for offers.) After a few months we found this was working so well that we decided to look for someone to live permanently with Meg. Since then we have had sometimes one, sometimes two young women who live there and go to work. Their responsibilities are to cook for Meg and socialise with her. In return we provide free board.

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I explained to Meg early on that she was now the woman of the house. It was her home and she should be responsible for it. She writes things on the shopping list, things she needs for her lunches usually. She conscientiously changes her sheets, and when visitors leave, it is Meg who strips the beds and remakes them. She still loves the bus trips and socials. When I was responsible for transport she would always ring a day or so ahead to remind me. Later she took to asking for my son whom I had been delegating to do the job. The girls now living there both have cars and they do this job now.

One year Marie and I as usual did the flowers in church for our mother's anniversary. This was not discussed with Meg. The service had just started, and there was Meg at the door. Without a word to anyone, she had got dressed and walked the couple of blocks. After that we included her.

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When Marie was ill in 1992, Meg called in every afternoon after work and they drank tea together. Then Marie went to Mt. Olivet. When Meg was taken to visit, she just sat quietly, caring but composed. She seemed to know what was going on without being told. Marie died of cancer in August 1994. We talk about Marie sometimes, but Meg avoids using her name.

At Christmas time it is now Meg who gets out the decorations. She reminds me about doing her cards, and she has a list of recipients. She makes up her mind about who should receive presents; sometimes she has definite ideas about what the present should be.

She has taken up new hobbies. One is patchwork, initiated by our neighbour Margaret Bell. Another is embroidery, initiated by an aunt. Meg has made step by step progress to the stage where she now arranges with this aunt (in Yarraman) a convenient time to visit, and can go both ways by bus. The aunt belongs to an embroidery group, and when Meg visits she is included in the sewing days. She also does long stitch embroidery. Incidentally this aunt and her husband describe Meg as a dignified woman.

Meg now does ironing for three neighbours. Ironing is always done at weekends, and even if she has been out on a Sunday, Meg will always get straight into the ironing when she returns home. If she will be away for a weekend, she herself contacts the women and lets them know when she will be back. Her arrival is always confirmed by telephone.

She is starting to become interested in cooking, prompted by another aunt who visited and taught her a few things. The girls who live there insist that she cleans up her own mess in the kitchen and she can do that.

At an early stage of her new life, Meg took over Mother's telephone book. She keeps in close contact with a small group of people, most of them are relatives. Others receive calls on important occasions only, such as a birthday, the arrival of a new baby, or when someone goes to hospital etc.

She recently organised afternoon tea for the birthday of my niece Naomi, who lives with her. Meg rang a few people, relatives and neighbours, and, with the help of a neighbour, requested a plate of food from some of them.

There is a wonderful group of neighbours there. Immediately next door is Margaret Bell who is a good friend. The back doors are very close, and the families have been in close contact for years. Margaret O'Brien lives a few doors away; she visited my mother every Wednesday for afternoon tea. When my mother died, Margaret O'Brien continued to come, did not miss a week, and now routinely has tea with Meg, sends her cards whenever she goes away, and invites her for dinner whenever they are having a roast. When I was away for her birthday last year, I received a phone call from Meg and Marg O'Brien (on a Wednesday, of course) asking if they could organise a tea party at Meg's to celebrate.

When I was away recently, Meg developed a very painful leg at work and thought she would not be able to walk to the bus. She had the workshop phone a friend who lives in Yeerongpilly, who drove her home.

Since Mother's death, relatives and friends from out of town still ring and ask for a bed, and people still pop in. One girl who was to fill in as a carer for a few weeks could not handle the fact that people would visit without first phoning, would even wander right in and say hello. She left. These people are in fact now visiting Meg as a person, she is no longer an appendage. These visits do two things: they provide continuity with her past, which was important at first, and they provide an opportunity for social intercourse, which is important in everyone's lives. I could go on and on with background, but enough is enough. I come now to what I see as the most impressive or conspicuous things Meg has accomplished since our mother died.

Meg has become more positive in so many ways. 'Positive' was a key word which someone gave her when she was first grieving. Meg wrote little notes for herself, some of them would be stuck on the fridge. They always said "Be positive". She would often say it to me with a smile. Even now she still brings it out occasionally.

She has developed her own circle of friends with whom she keeps in regular contact. I notice that this circle is growing. Most of the phoning would be done by Meg, but the friends respond positively (is there a better word?). I think they enjoy the contact, even if they were first motivated by their friendship with Mother. Personal visits supplement the telephone calls – people call, and Meg visits. I notice that some have been dropped from the telephone routine, and I am sure that is because she did not get a positive response, these people did not keep up their side of the relationship.

She reminds me when she has to go for her 2-yearly checks with physician or ophthalmologist. She makes her own appointments with the local hairdresser, is not upset by change of ownership or change of premises – she just phones me to make sure I will send in the money. She handles the dentist completely independently, going monthly to have her gums checked. Dental care involves a nightly fluoride application using an appliance like a mouth guard, which she does herself, more reliably than most of us would be.

She knows when she needs new clothes: I am summoned to discuss her wardrobe twice a year at the change of seasons, and at other times to discuss underwear, nightwear etc. We have replaced her old sewing machine and typewriter, but she now thinks she would like a word processor!

I suppose to sum it up, we could say she has grown up a lot, she has matured and become quite independent. Sadly, this could not happen while our mother lived, her death opened the door for Meg to become much more adult, a separate identity. But this development depended on the training and example which our mother had provided. Mother was a quite remarkable person, admired, respected and loved by all who knew her.

I believe that her recent development was facilitated by two factors: first, keeping her in her own home and second, the support of relatives and friends. The disorientation of a shift would have cut her adrift from all her usual domestic routines; it would have placed her again in a subsidiary position in the home of one of her sisters, or even more so in a community care home; it would have separated her from the supportive network of neighbours.

The decision to keep Meg in her own home was easily made, as Marie lived directly opposite and the two households were in constant contact. Just as important was the fact that there were sufficient funds in my mother's estate to provide for the upkeep of the house. As time has passed we have discovered that the pension Meg receives covers a larger proportion of her expenses than we had at first expected. We hope to have sufficient funds to pay a housekeeper if it becomes necessary in the future.

Since Marie's death, I alone have ultimate responsible for Meg's wellbeing, her health and happiness. I am responsible for the maintenance of the house and garden, and we employ good routine cleaning and gardening help. I am sure this could become onerous were it not for the family and friends who help so much, and the support of my husband.

As for financial arrangements, I handle Meg's pension and I have signing rights on her bank account, for which my husband is trustee. I also have a separate credit card which I use exclusively for her expenses. My husband as my mother's trustee handles the estate.

I would like other families to know that their handicapped children can have good lives when left without parents. Meg is not only well and happy, but has matured and become independent to an extent we would never have believed possible.

Part 2: 2002

Meg is now nearly 56 years of age. She still lives in our mother's home, still with a carer. In 1996 we celebrated her 50th birthday with a gathering of about 35 friends and relatives here at our home. She had long anticipated this event and took part in deciding on the guest list. She made a nice little speech. Afterwards she told me she was looking forward to her 60th. She still attends the monthly socials and bus trips though I notice she misses one occasionally through forgetfulness. She is still fond of the telephone, though she has little to say and the calls are short.

One significant change is in her weight. She was always inclined to being overweight, and our doctor warned me that in time her knees would become troublesome. So we instituted a diet program and she has lost 30 kilos, down from 95 to 65. She has an exercise bike and a walking machine. She is very methodical about using the equipment, making ruled pages for each day and marking off the time she sets for herself. She is still very fond of food and I am sure that weight control will be an on-going consideration. She still goes to the sheltered workshop and hates to miss a day for any reason.

The biggest change since 1994 is that Meg has gradually become too conscious of her own health. She is not a very cheerful person now, though some people have a happy knack of carrying on with a bit of nonsensical banter that she does enjoy. She talks about herself too much, wanting people to take her pulse, complains about little pains here and there. She talks to anyone who will listen about whether or not she should take tablets as prescribed. And having read that Alzheimers disease is common in older people with Down syndrome, we have decided to consult a psychiatrist, the idea being that we may be able to pick up early signs. We still accept that the time might come when Meg would need a paid carer.

To sum up the situation now, I am still satisfied that we made the right decision in keeping Meg in her own home. I do not think that the gradual decrease in her cheerfulness is due to her domestic arrangements, but rather part of her aging process. We have been fortunate in being able to find thoughtful and conscientious carers. We have to face retirement from the workshop and finding other suitable occupations.

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