

A Serious Case of Empty Nest Syndrome

Edel Harris
June 2010



My son Ross is 23 and was diagnosed with fragile X syndrome when he was 5 years old. The early discussions we had with our GP painted quite a bleak picture – “he won’t be able to tie his shoelaces”; “he won’t be able to ride a bike”; “as an adult he may require institutional living.”

I’m pleased to say that, although it hasn’t all been plain sailing, Ross is now living a life that far exceeds the expectations we had for him in those early days.

In his late teens Ross’ behaviours were challenging. As a family we went through a difficult time as we tried to understand his anxieties and the things that triggered his challenging behaviour.

We also came to realise that, although he was very happy living at home with his parents, he was observing his younger brother grow up, move into a flat with his friend, have girlfriends, get a job and go to University. We could see that Ross was struggling to deal with the very obvious differences between his own life and that of his brother’s. He also appeared to see us as the blocker to a life of freedom.

Working in the field of social services myself, I often see the very real challenges presented when older men with a disability, usually in their 40s or 50s, suddenly lose their parents and have to cope with a sudden and un-planned move out of the family home, where they have lived and been cared for all their life. We didn’t want Ross to face this situation and decided to plan a transition from living with us in the family home to him living in supported accommodation in the community. We began this journey two years ago when we first started to look at the options available, with the support of Ross’ social worker and care manager.

It soon became apparent that there were no vacancies within any social housing or care provider organisations in Ross’ home town. We were offered residential care in other towns nearby, but instinctively knew that Ross would be happiest living in his home town, close to us, and within a community that was familiar to him and one in which he was well known. We also

ruled out the option of shared residential care because Ross' communication difficulties and anxieties would only be exacerbated if he was to live with other people with a disability.

So we decided to buy a flat for Ross in our home town, within walking distance of our house, close to the railway station and the town centre. We also began discussions with the local authority and the Independent Living Fund (operational at the time) about the level of support Ross would require and the all important funding package.



Finding the right accommodation was the first challenge as we needed a two bed-roomed property to accommodate a sleep over room for the support staff. The flat Ross lives in has proved to be perfect in terms of size, layout and location, but, unfortunately, we didn't foresee the problems associated with being a resident in a block of 3 flats. Ross is very sensitive to noise and he really struggles if he is deprived of sleep. Some of Ross' neighbours enjoy having parties and playing music in the early hours of the morning. Ross gets upset when this happens and it has resulted in him "running away" in his pyjamas in the middle of the night and in him becoming upset, with the resulting difficult behaviours.

The next issue to address was to choose the care provider. Ross was already receiving some support from two care organisations. It was very important that, through the transition phase, Ross had consistency of support from people he already knew, so we managed to convince the care manager to keep both organisations as part of the care package. There is an on-going issue related to funding, where one of the care provider's hourly rate is £7.00 more than the other and the council will only cover the cost of the lower rate. However, Ross now has a regular team of 4 male support workers who provide the day to day care and support that he requires.

The move into the flat was very gradual. We began with some initial visits and tried to get Ross interested and involved in choosing his furniture. Then he spent a few hours in the flat during the day a couple of times a week with his support workers, preparing and eating a meal.

For his 21st birthday we bought him Man Utd TV for the flat, which provided a great incentive for him to want to spend more time there.

He stayed overnight one night a week, then two and gradually we increased the number of nights he spent away from home. Then on November 1st 2009 Ross moved into his new home and life has never been the same since.

Ross loves living in his flat. With support, he is managing to do so many things that we never thought possible.

He enjoys a very full and active life that includes three ‘voluntary’ jobs in a local hotel, a wine shop and a gift shop; two days at college; he is a member of the local swimming club and trains with them once a week; he regularly goes to watch his local team play football and enjoys a social life with his brother and his brother’s friends.

When we go to visit him in the flat, he proudly offers us a cup of tea and is like a king in his castle, so proud of his little flat and so pleased with how well he is doing. It hasn’t all been plain sailing and we still get difficult days when Ross’ anxiety levels are such that his behaviour becomes problematic. We still get the regular phone calls from him when he is upset or worried about something and we continue to play a very key part in his life.

As his Mum and his main carer for all of his life, I have found the ‘moving on’ process quite painful. When we were in the middle of planning the move I was so caught up with the practicalities that I hadn’t taken time to think about the emotional impact this major step would have on the family, especially me.

The house is so quiet. I am at home on my own for periods of time and although it is liberating and relaxing (and I get to choose the TV channel!) I still find coming home to an empty house quite distressing.

Ross was always there. Ross was always the first consideration when we were planning anything. My work commitments had to fit in with Ross’ support needs and I always had to rush home at the end of the working day to ensure Ross’ supper was ready at a certain time. We couldn’t always say ‘yes’ to invitations unless they included Ross and any time away as a couple had to be very carefully planned in advance so that Ross was looked after and catered for.

We no longer have to go to bed when Ross is ready to go to bed; we no longer have to eat when Ross is hungry; we no longer have to creep quietly downstairs in the morning for fear of waking him up. We no longer have Ross charging into our bedroom at the weekend and we no longer have the constant joy of his company.

It is not that I miss him; we see him almost every day. It is simply that I no longer play that most important of all roles – being the person who is responsible for his wellbeing and happiness. As a mother, what more could I want than to see my children fly the nest and make their own way in the world, enjoying a quality of life we all aspire to?

When I look at Ross, the young man, coping with his disability and living such a full rich life, with the support of others, I’m really very proud of him (and if I’m honest I’m a little bit proud of myself too!)