



Family Carer: Jo McGee
Age: 81
Cares For: Ian
Situation: Lives at home
Age: 50
Cares For: Danny
Situation: Lives in Supported Living
Age: 48

Years of Caring: 50

'It doesn't stop when they are 50 – it's a life sentence!'

Jo moved to Oxfordshire from Wembley, London in her mid-twenties with her husband John when he was offered a job in the area. She was a teacher, a job she thoroughly enjoyed and something she would have liked to have done full time but caring for two children who had learning disabilities meant that she had to give it up.

When Ian was born 50 years ago and it became apparent he had a learning disability Jo and her husband were asked if they actually wanted to take him home. Jo's response was 'this is my son and nobody else will look after him'. No one else in the family had a child with a learning disability and they like many other families 'didn't think it would happen to us'.

Danny was born 2 years later but did not get an official diagnosis of Fragile X until he was 18. The boys had to go to different schools and one of the hardest decisions that Jo and her husband had to make was to send Danny to a residential school in Shropshire as he struggled to fit in to the special unit at the local school.

At the time she felt it was the best option, but looking back now she is not sure that it was the best choice. Like many older family carers Jo struggles with guilt about the choices she has made for both her boys and whether she has done the right thing.

In 2006 she lost her husband John. She found this hard as she did not have someone to bounce ideas off. She has been a single family carer for 13 years.

Some of the best bits about being a family carer are the brilliant moments she has with them when on holiday. Been told by a fellow passenger on a cruise that her son Ian had made their holiday is one memory she will never forget. Ian is also very helpful and makes her cups of tea! The boys 'fight like cats and dogs' when they are together but Danny is equally very protective about his older brother.

The hardest thing is the fact that she cannot do anything spontaneously. A lot of planning is involved to do anything. In the early days when the boys were young they needed a lot of care and physical support and even though Ian is independent to a certain extent he can only be left on his own for very short periods of time otherwise he will dial 999. Jo has a very good relationship with the local police! And even now he still likes to go to various clubs and evening activities which Jo is still supporting him to do.

The boys have bought a mixture of fun and worry in equal portions. They are great company and make Jo laugh. Because of them she has met a lot of famous people - something other people have not been able to do. The boys have been a 'life changing experience' but she feels she is definitely a better person because of them.

Her greatest worry is what is going to happen to them when she is no longer around and so she has to make sure that she has everything sorted. Even though Danny is in supported living and has good support he still contacts and sees his Mum all the time. Her hope is that they will always have someone to love and care for them, that someone will always give Ian a big hug and that he will be able to continue to live in the house he shares with her. She still handles the finances for both the boys and has Power of Attorney for both.

When asked what the difficulties have been raising two children with learning disabilities Jo found it hard to answer. She doesn't deny that life has been difficult at times but equally it has also been brilliant. She has never known what it is like to be a 'normal family' or not to have a child without learning disabilities so for her this is normal. She is able to ask friends for help as trying to get help from adult social care 'is like banging your head against a brick wall'. She encourages families to get on with it, enjoy it and see it as an opportunity. Life will be different but it is also rewarding.

Her advice to other family carers is to 'expect the unexpected and embrace whatever happens as it's not what happens to you but how you deal with it' that is important. 'To some people what is a tragedy is to others a blessing'. She feels family carers are the experts on their own children and that having a learning disabled child teaches you to be a fighter. 'For what every family takes as normal you have to fight for'. Before Ian was born, Jo said she would not have said boo to a goose! She would not have dared to tackle politicians but now she says 'bring it on!'

The reality however, as Jo herself says 'It doesn't stop when they are 50 - it's a life sentence'.