

## **MEET JOE**

### **THE STORY OF A MAN WITH PROFOUND LEARNING DISABILITIES**

- November 1948 Born in local hospital, 3<sup>rd</sup> child of working parents, hospital notes read “low birth weight, floppy baby? Prognosis poor. Unable to feed normally. Lack of bonding”. He remained in hospital for 2 months, spending his first Christmas there.
- January 1949 Returned home to be with parents and 2 brothers near London. Parents told that he would be unlikely to survive more than a few months. In post war England, with the NHS very new, there was very little support or advice for families with disabled children. People were mainly left to get on with things as best they could.
- July 1951 First family holiday, parents and older brothers went to the seaside for a fortnight, Joe was admitted to a children’s hospital. He was in a ward of thirty children with similar disabilities. He could not sit, and at that time no one knew that he could not see, so he lay in a cot surrounded by unfamiliar sounds. Although the nurses were kind they were too busy to spend time with him and he felt very frightened. These “respite” stays became more frequent over the next couple of years, and Joe always felt a huge relief when his Dad came to take him home.
- March 1953 Admitted to hospital with measles, which turned to pneumonia, he was very poorly. A doctor’s report stated that his lack of alertness, general spasticity and failure to meet normal milestones indicated severe subnormality and recommended institutional care.
- December 1953 Christmas preparations were underway and Joe was admitted to the children’s hospital for a two week stay, his mother was expecting again and finding things difficult. The stay was extended as the baby (a sister for Joe) came early, but Joe never returned to his family home. He moved to a long stay ward with a day room where a teacher came every day to conduct “lessons”. Joe began to have regular physiotherapy that helped his painful spasms, he was given a special pram so he could be moved about and sometimes went out in the sun which he loved. There were very restricted visiting times, his parents were only able to visit once a month. He never saw his brothers or sister.
- April 1956 Joe was admitted to the surgical ward for a bi-lateral Achilles tendon release, following surgery he developed double pneumonia and “complications to the lungs”. He found himself, once over the worst of the illness, on the respiratory ward with both legs in full plaster lying in his bed. Due to the nature of the ward there was no visiting, TB was still a real problem in those days, he remained there for 8 months.
- September 1960 Joe’s father accepted the offer of a new job in the Midlands, the family moved there, and there is little mention of them in Joe’s notes for many years. He continued to receive birthday and Christmas cards for a while. Joe was now attending a special school in the grounds of the hospital, it was much more suited to his needs and it was there, with the help of his favourite teacher, that Joe began to develop his love of music.
- July 1961 Joe was chosen to present a gift to Princess Marina, Duchess of Kent when she visited the hospital as the new patron. He had his first pair of smart

trousers and was propped up in his wheelchair for photographs with the royal visitor. Apart from this special day, the patronage changed things for children living in the hospital as she started a fund to give them all an annual holiday and regular coach trips. Joe began, really for the first time, to experience the sounds of the world outside the hospital.

July 1967

Joe left school.

August 1967

Joe was transferred to a long stay hospital for adults. He was given no explanation about the move and only a few of the people he had lived with for many years went with him. It was very different from the children's hospital, with strange, loud and frightening sounds, lots of people rushing about, unfamiliar staff feeding him and dressing him in unfamiliar ways. The comforting school routine was replaced with occasional visits to "day services" which Joe found noisy and bewildering, and "workshop" where he sat surrounded by a cacophony of noise for 2 hours twice a week before facing the anxiety of another meal.

However, there were oases of relief, Joe loved his weekly music therapy, especially when his therapist played the flute, it often made him very sad, but she did not tell him to cheer up, but supported him in his mood. There were often concerts on the ward with all sorts of music, some people who sang or played an instrument beautifully and some who were so awful that, if he could, Joe would have covered his ears, but he still enjoyed himself! Best of all was meeting Peter, his special staff member (or Keyworker as they were later called). Peter understood him even though he couldn't talk, he just seemed to know what Joe wanted or needed and was so careful when helping him that Joe didn't feel afraid. They laughed a lot together and over the years went to all sorts of places. Joe didn't like Peter's days off even though he knew that he would be back soon.

November 1969

Joe's 21<sup>st</sup> birthday! He had a birthday cake but no one remembered it was a special birthday.

May 1970

A hydrotherapy pool was opened at the hospital, and Joe started weekly sessions. It was the first opportunity he had ever had to be free from the confines of the straps of his wheelchair or the pillows and rails on his bed, he loved it! Although he couldn't move his arms or legs very much on his own, his therapist pulled him through the warm water fast, and with a rubber float supporting him he could float completely and absolutely on his own – it was a wonderful feeling!

January 1972

Joe was admitted to hospital for ten days with a chest infection, Peter was with him during the day time so it wasn't too bad.

March 1972

Another admission for a chest infection, five days this time.

June 1982

Joe and Peter and some other friends went on holiday to Clacton. Joe had three new experiences, having a drink at the pub, visiting a fair and going for a trip in a boat, he was 34 years old.

October 1982

Joe was admitted to hospital with a fractured head of humerus (arm). It was not known how this occurred. While in hospital he developed a chest infection and pressure sores on his bottom and heel, he could not sit in his

wheelchair for several weeks or attend any of his activities, including hydrotherapy.

- November 1988 Joe was suddenly transferred to another long stay hospital. He arrived at his new home in a borrowed, unsuitable wheelchair with all his possessions in two black sacks. Peter stayed behind, he did visit Joe a couple of times but then stopped. Joe slept in a smaller room, not a big ward, with three other men. There were similar things to do, day services, music and hydrotherapy but Joe felt very lonely and unsettled for many months.
- May 1990 Joe was admitted to a local hospital for tendon releases on his arms. It was a major, very painful operation to move his arms from a flexed position with his elbows bent and his hands under his chin to a much more open position which made dressing easier and enabled him to use his hands a little. He was in plaster for a long time and then had daily physio which he enjoyed as there was always a good selection of classical music playing in the department.
- April 1992 He began to attend an occupational therapy centre where there was a sensory environment called a snoezelen. In the snoezelen he was able to see one light source shining in the darkness and make out a few shapes, there were sounds and smells and a feeling of security that was new to him. He began to work with the staff to use a switch, soon he understood that if he pushed the switch the fan came on, blowing into his face and if he pushed it again it went off. Over the years he developed this skill to operate other pieces of electrical equipment.
- July 1993 Joe went abroad for the first time and stayed in a hotel, it was quite an adventure. He went with his keyworker and two of his friends from home. They went to Lourdes in France on an aeroplane, and although Joe found this rather alarming as he had never experienced anything quite like it, he was reassured by the air hostesses who allowed him to lie across several seats as he could not sit very well. Lourdes was full of music, there was church music every day in the streets and in the church, disco music in the hotel and they sang songs on the coach when they went for trips out in the countryside. Shortly after this, the rules about disabled people travelling in aeroplanes changed and it has not been possible for Joe to fly since.
- September 1994 Joe moved to a different home in the hospital, he visited several times before he moved and his keyworker and one of his friends, George, went too. He shared a room with George, but George did not like music in the bedroom, he preferred the television which was always on. Joe did not like television much as the talk often prevented him from hearing what else was happening in the home.
- December 1994 Joe had a surprise visitor, his eldest brother Sam, suddenly arrived at the Christmas party with his wife. They stayed for the whole afternoon and Joe was so pleased that they were there even though Sam said he didn't know who they were. Joe's keyworkers, Peter and more recently Jim, had often spoken about his family who lived a long way away.
- November 1998 Joe's 50<sup>th</sup> birthday! He had a special party in the hall of the hospital with lots of people and all his favourite music. He wore a new tie and waistcoat and Jim had given him a special birthday shave and some nice smelling aftershave.. Sam, his brother came with his family and also Joe's sister

whom he had never met. There were lots of children but Joe didn't know who they were but were included in the family picture. It all went too quickly but Joe was very tired when he went to bed at 8 o'clock that evening.

- December 1999 New Years Eve, a new millennium! Joe went to a party in the hall with everyone else from the hospital he wasn't sure why, but the music was good. He had to go to bed early as they were short staffed.
- May 2000 Some new people started to visit the home every Thursday, Joe noticed them first as they were singing the song that his mother used to sing him, "You are my sunshine". The following week, they came over to him and introduced themselves as Us-in-a-Bus, Joe liked the song they sang as it had his name in it. He acknowledged them, using his voice, and they replied, he was surprised, and they had a little "conversation". They included him in a game with the others in the room. Joe enjoyed it and looked forward to their visits.
- July 2000 An assessment, carried out over several months reported that Joe should be supported within an environment suited to his visual impairment. He found that more people were touching him on the shoulder before they moved him, people were helping him to touch things to aid his understanding, there was music in his room to help him know what time of day it was and different smells in different rooms so he knew where he was. At first it was strange, but after a while he began to feel less anxious about things.
- March 2001 George disappeared, Joe did not know where he went, but for the first time he had a room to himself. It was strange at first but Joe soon began to really like having his own choice of music on or no music or tv at all. Jim took him out to the shops and they bought some special lights and a bubbly lamp for his room. People began to knock before they came into his special room instead of just appearing, he enjoyed some privacy for the first time.
- March 2004 Jim, his keyworker left. Joe did not understand why he would not be there anymore, there was a party to say goodbye to Jim but Joe did not feel like having a party. He felt very sad and missed him for a long time.
- October 2007 Joe eventually moved out of NHS care into a bungalow with two friends. The house was especially designed for people like him who could not see, it has special lights so that he can see a little better and there is space for all his possessions. For the first time Joe has an overhead hoist which makes life much less stressful for Joe and his carers. Between them, Joe and his friends have use of an ordinary looking car which his wheelchair will go into. In the hospital, Joe always travelled in a large bus. Joe goes out most days to the shops, to play boccia or to the new hydrotherapy pool.
- November 2008 Joe's 60<sup>th</sup> birthday! Joe went out for an evening meal to a restaurant with his friends, a few days later he went to a concert of sixties music and they sang him Happy Birthday!
- March 2009 Joe was been told that he will be moving to a flat on his own which is being specially built, it will be ready in about a year. It will be in a block with several other people who live near him now. He will have an assistant whenever he needs one to help him in his flat or to go out.