



## Robin's Story

Robin is Downs. He is 65 years old and is now on the downward slope of Alzheimer's Disease.

When he was born in 1957 he had a life expectancy of, at most, 40 years. And that only if he were to receive proper health care, were enabled to live an active, healthy life-style and encouraged to reach the full potential of his 20 to 30 IQ.

Many of Robin's contemporaries were shut away in large institutions, the stigma of having a "mongol" child being too much for many parents to bear.

Our parents decided on another course. Robin would have as normal an upbringing as possible, would have the same opportunities as any other child born into our family.

There was not an easy choice. With the stigma came comment and stares. When fighting for his life in an oxygen tent as a baby the nursing sister "comforted" our mother by suggesting that his imminent death "was probably for the best".

In later years our mother described to me the rage which that comment ignited. With rage came a steely determination to fight. To fight for Robin's right to an education, to fight for his future adult life.

As a result of that fight our parents ensured ESN (Educationally Subnormal) education for him. The authorities had him down for SSN (Severely Educationally Subnormal). His state education ended when he was 16 and under "normal mentally handicapped expectation" he would have mouldered at home, or in an institution – that is a large hospital with wards full of mentally subnormal children and adults. Our mother regularly visited one of these and would return home in tears at the desolation of those abandoned people.

Robin was fortunate. Ours was not a wealthy family, but there was sufficient money to send Robin to what our father described as the "Eton of education for the mentally handicapped", St Christopher's School in Bristol. Here at the age of 16 Robin embarked on a two-year pupils' training course. Here he was taught life skills, learnt to live away from home and, to his horror, was placed on the weight-watchers' table so that his diet could be monitored to maintain a healthy weight.

We missed him terribly at home but for him it was the stepping stone into adult life, as University was for me.

The difference, of course, was the prospect of what came next?

I would be able to take up a career, support myself, determine my own way in life.

Robin would not. He would be dependent on care and support throughout his life and the fear which haunted our parents, the fear which haunts all parents of children born out of the "norm", was what would happen to him when they died, or could no longer care for him?

A tiny personal ad in The Times in the mid-1960s caught their attention. They made contact and from there joined with others in similar circumstances to support Peter Forbes in his visionary mission to establish a life-long, "village" home for people like my brother. CARE (Cottage and Rural Enterprises) was born. My brother set out on his adult life adventure at Blackerton in Devon aged 18. Nearly 30 years ago he moved to Rowde in Wiltshire with more than 12 others, the first people to move into the new, purpose-built CARE "village" at Furlong Close.

His "village" life has enabled him to work in cafes and pubs, to experience a great deal of foreign travel, to make life long relationships, to socialise, to take vocational training and gain qualifications at his own level. He has had the freedom to visit and socialise with his neighbours on the five-bungalow estate free of the supervision he has to have for his own safety whenever he goes off-site. In other words he has had a very full, active, healthy life. Defied the odds and although now with Alzheimer's Disease continues to defy his prognosis and is living remarkably well despite his dementia. He has had a "normal", inclusive adult life among people he identifies with, people he knows, people he trusts. He has been protected from the dangers, derision and cruelty posed by "normal" society.

Fast forward to 2020 and the charity which took over CARE at Furlong Close, HFT (Home Farm Trust) announced it was closing Hft Rowde and that within nine months all the then 34 adults whose home it was would be moved out and relocated by Wiltshire Council Adult Social Care in Supported Living provision in ones and twos around Wiltshire.

He would have been placed in a Supported Living flat or house in a town. As a person unable to leave the immediate environs of his home without supervision he would have been trapped behind his own front door. Perhaps with one or two others. He could not have visited friends and neighbours without the attendance of a key worker. He would not have had access to the open air, the gardens, the orchard, the craft rooms and workshops at will.

Thankfully a determined campaign by families and friends has succeeded in Saving Furlong Close. Now it is a community of five bungalows managed by a specialist housing provider with care commissioned by Adult Social Services. The style of care has changed to put the focus firmly on the wishes and needs of the individual. Care is person-centred, but thanks to the "village" design of Furlong Close the freedom to be truly individual within a large – seven acres – site has been preserved for the current people who live there and for those who CHOOSE to live there in the future.