

Chapter II

Susan's parents had noticed her unusual method of reading and forming S's but believed this was just an idiosyncrasy of hers. She grew by about four inches that year which they thought was strange, but for them this was no clue to what lay ahead. "We wondered why she failed the Eleven Plus but there was no explanation," says Les. The initiative of Homewood's head teacher in referring Susan to the doctor, with the use of the term "spastic", was the first inkling her parents had that anything could be medically wrong.

Meanwhile the family lived for a year in the gardener's lodge of Biddenden's Hendon Hall, today a separate property called Field Cottage. When the owner, Mr Shingles, sold up he suggested the Leneys accompany him to Hurst Green but they declined.

Through the council Les and Norah obtained a house on a new estate in Biddenden called The Weavers, of which they were the first occupants and where Les still lives. Les hired himself out as a self-employed gardener and today can point to a number of properties in the village where he has worked in the past: "There were plenty of jobs going around". Chief among these was Biddenden Place, a large property in the centre of the village: "I worked a lot there," he says.

Among the important memories of those days were the church fêtes that took place, sometimes at Biddenden Place, sometimes at Hendon Hall or the adjoining Gardener's Lodge. These were real community occasions, very good days out. He remembers one, he thinks in 1962, which raised £1,000 which was a great deal of money at the time. Susan was well then and she entered the fancy dress competition as Little Bo Peep.

Les paints a vibrant picture of community life in the early '60s. The very successful church fête inspired some boys to put on a variety show the following year. The show became an institution, selling out year after year and giving rise to the Biddenden Entertainment Society. Performances packed the village hall, recalls Les: "You sat on anything you could get your hands on."

Les mourns the passing of that era. When the family first came to Biddenden in 1960, the village was "just about a farming community". But despite the loss of its railway station, swept away in the Beeching reforms, some people began to move in who did not work locally but commuted elsewhere. "Progressively the village has lost its impetus to make fun and games," believes Les.

Susan with
friends in
July 1960.
Clockwise
from top left:
Susan Leney,
Susan Farris,
Stella Farris,
Sheila
McGuire



The Leneys became well known in Biddenden. Their friends included the Lanes and the Farris's who are still closely associated with the village. Dorothy Farris, mother of Susan Broadbent, remembers Norah as a very particular person who kept her house spotlessly tidy and was always immaculately dressed. Recalling that Norah's brasses and woodwork always shone, she says: "I used to go home and wonder why mine weren't like that. The place glowed and yet

it was always homely. You didn't feel embarrassed to sit down."

Norah was the organiser in the family. She made sure Susan continued to see friends she had made at John Mayne School. The friendship with Susan Broadbent was fostered by Norah who regularly suggested they meet up.

Susan Broadbent remembers: "I always felt Susie had something to say that she couldn't quite get out, couldn't express. There was a sadness behind the eyes. She couldn't do the things she wanted and you never knew how much she remembered of the time when she was healthy. She was a lovely girl really."

Susan's condition worsened slowly and inexplicably. She was increasingly clumsy, she could no longer co-ordinate her hands well enough to play the piano and at 13 she gave up. Les remembers selling the piano. He also remembers Susan running towards him, tripping on an uneven pavement and sustaining the kind of fall normally reserved for unsteady toddlers.

Les recalls that Norah visited a specialist in London on the recommendation of the family GP, Dr Tower. This person established that Susan was an only child before admonishing her mother: "You're just worrying too much".

And yet something must have been wrong, because Susan was unable to remain at Homewood. Her increasing clumsiness and slowness made her the butt of school mates and she found it hard to keep up academically.

Les recounts how some educational officials came to assess her when she was 15 and suggested sending her to board at Laleham, a private school in Cliftonville, the furthest point of Kent's Isle of Thanet. Les and Norah were told initially this would cost a lot of money but in the end the fees were covered by the NHS. Les said: "Our trouble was travelling to and fro." Even this did not last. One day when Susan was taken swimming, she got out of her depth and had to be rescued. Laleham quickly concluded it could no longer look after her. Les and Norah were asked to take her home.

What the doctors saw

The doctors take up the story again from around 1965, while Susan was still at Homewood. They noted that she was emotional and cried easily, frequently tripped up and had to grip things to stop herself falling. Her hands shook as she approached objects she wanted to pick up.

Nevertheless, it was not until 1967 that Susan, aged 16, came to the notice of the neurologist Dr R. Kelly who was to supervise the unfolding of an eventual diagnosis some years later. At the Maida Vale Hospital for Nervous Diseases in London, where Susan's GP had had her admitted, Dr Kelly promptly ruled out any treatable lesion on the brain caused by encephalitis (a rare complication of mumps) or a tumour. Instead, he found that Susan's symptoms emanated from a region of the brain near the spine, called the cerebellum and concerned with motor control.

By that time Susan was uncoordinated in her movements and gait, had problems directing her eyes where she wished, spoke slowly and indistinctly, forgot where things were in the home and displayed a remarkably low IQ (84) for a girl who had shown so much early promise. An EEG confirmed abnormalities in the brain, but still there was no clear diagnosis and no solution for Susan. Dr Kelly wrote later of that first round of investigations: "We did not find anything of any great importance".



Left: Susan and Norah at Winchelsea Beach; below: Les and Susan in the garden at Down Cottage, Rye



Above and right: in the garden at Sask Cottage in Iden

