

Katie's Story

My daughter, Katie, was a happy child and apart from niggling health problems... allergies, eczema, asthma and sinusitis, we were completely unaware of the more serious conditions which were hovering in the background waiting to impact and have a profound effect on her life.

At the age of 16, Katie started to complain of pain in her hips when walking. During a family holiday in the Lake District, a ballet teacher staying at the same hotel noticed Katie had one hip higher than the other. We immediately arranged for her to seek medical advice on our return home. Four doctors' gave varying opinions, including sciatica and growing pains but no-one diagnosed a spinal curvature.

Unhappy with these diagnoses, we arranged for Katie to see a spinal surgeon and she was duly diagnosed with scoliosis and a 45 degree curvature. She underwent several more tests including a lumbar puncture, a myelogram (where a dye is injected into the spinal sac) CT scan, nerve tests, MRI scans and x-rays, which showed a syrinx (a cavity) in the lumbar region of her spinal cord.

Katie was referred to a neurosurgeon, who diagnosed a condition called syringomyelia. This is a progressive condition which can cause paralysis of the limbs, usually caused by a spinal tumour or hindbrain hernia; Katie had neither. We arranged for a second opinion with another neurosurgeon. He disagreed with the first diagnosis and was rather mystified as to why Katie had developed a cavity in her spinal cord.

Katie had major spinal surgery lasting 7 hours which involved the removal of 5 discs, a rib and the placement of a titanium rod which was screwed into her spine in the lumbar region.

After the operation she spent two weeks sandwiched between a special bed which rotated her body every four hours and then a further 6 months in a plaster cast, during which time she continued with her 'A' level studies. Finding clothes to fit over the cast was a problem and also finding a comfortable position to rest. Katie spent

most of her spare time lying on the floor... the only comfortable position to relax in!

12 months after her surgery, Katie had a second MRI scan which showed that the syrinx had completely disappeared. This really baffled her neurosurgeon as syringomyelia is a progressive condition.

Seventeen years later, Katie still suffers from neck pain, sciatica and pain in the lumbar region of her back. She cannot stand or sit for longer than 1 hour without being in discomfort.

Surgery was the only option for Katie because her internal organs were being crushed and she considers herself lucky to be leading a fairly normal life.

My daughter's experience has made me determined to research the possible causes of scoliosis and to investigate alternative treatments which may prevent the need for surgery.