




Neelam's story

After years of visiting her GP with severe headaches, vomiting and dizziness, Neelam was eventually referred for an MRI scan which discovered a large brain tumour on her pituitary gland.

The impact of the brain tumour and the subsequent surgery left Neelam with extremely complex mental, physical and behavioural healthcare needs. After multiple admissions to neuro-rehabilitation services, who struggled to manage her complex needs, Neelam was admitted to St Andrew's Healthcare in 2019, where a *non-medication neuro-behavioural* approach offered her and her family hope and a way forward.



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The beginning of Neelam's health problems

For a long time, Neelam knew she was not well. She was withdrawn and depressed with constant headaches, vomiting and dizziness.

The discovery of a brain tumour was devastating and the life-saving surgery at Addenbrooke's hospital in Cambridge was a scary and traumatic experience.

The surgery was successful, but due to the physical nature and a partial resection of the tumour, Neelam was left unable to regulate many of her bodily functions. Damage to her brain means Neelam is unable to tell when she is full, leaving her in a constant restless state of feeling that she needs to eat or drink. Fluctuating sodium levels and thermoregulation problems causes her to become confused and frustrated, which can result in extreme mood swings and aggression towards family and staff.

Neelam was assessed by numerous care homes and private hospitals who declined to accept her for rehabilitation due to her complex mental and physical health needs. After a prolonged period of admission at Addenbrooke's, where they struggled to manage her complex needs and give her the consistency of care that she needed, Neelam was admitted on a Deprivation of Liberty Safeguards (DoLS) order to the charity's female brain injury ward. Elgar is a 12-bed service for adult women who have an acquired or traumatic brain injury and is part of Kemsley neuropsychiatric services.

Staying at St Andrew's

Neelam came to St Andrew's exhibiting memory problems, variations in her mood, irritability, preoccupations with food and fluctuations in her sodium level. The sodium level changes were due to her brain injury.

On admission the clinical team on Elgar closely supervised Neelam and took blood tests regularly throughout the day to monitor her sodium levels. Neelam struggled to understand why this was required but staff were consistent in explaining their approach and when Neelam started to feel better she started to settle and trust the clinical team.

Neelam says *"At the time I was frightened, I didn't really know what was going on. I had very mixed feelings about being moved to a new hospital. I had been brought to a new place, full of new people. But the staff were very nice and helpful, and they explained everything to me."*

Neelam was assessed using the Honos-ABI, FIM+FAM and START clinical assessment models to monitor her clinical progression. The clinical team spoke to previous hospital teams and worked with Neelam and her family to decide on a non-medication, neuro-behavioural care plan that supported Neelam's holistic needs and would help her to gain greater independence and eventually move her towards returning home to her family.

The non-medication, neuro-behavioural approach aims to improve brain function and understanding through various neuro-motor, neuro-cognitive, neuro-emotional, and other neuro/physiology-based activities and therapies which reduce risk and increase learning opportunities. These activities have helped Neelam to structure her day, establish routines and use her positive behavioural plan (PBS) to manage her behaviours.

The extensive range of activities that are available on-site for patients at St Andrew's has been key to Neelam's on-going

recovery. As a former pharmacist, she has always had a thirst for knowledge and learning so she was keen to start sessions with the Adult Education Team and reignite her love of maths and education.

Neelam's weekly schedule soon included jewellery making, ceramics, tapestry and taking part in any of the arts and craft sessions that are regularly held at the St Andrew's activity club and Workbridge, our vocational education service. She has become a key member of the ward, assisting patients when they first arrive and helping them settle and she supports medical students in their placements and understanding of brain injuries. During the pandemic, Neelam led other patients to create hand-made Christmas decorations, which lifted their spirits ahead of the festive period.

She says: *"Coming to St Andrew's was a real turning point for me. In the beginning I was very quiet and lacked confidence. But, slowly and surely I've built that back up again and I've started doing the things that I really enjoy."*

Dr Kevin Beckles, Neelam's Clinical Psychologist says: *"Not a day goes by when Neelam isn't out and about somewhere in the charity taking part in some sort of an activity. She's smiling again and it's a real joy to see."*



The next step for Neelam

Having received dedicated ward-based care Neelam and her family have just been told she is well enough for the next stage in the recovery.

This will involve her moving into a supported transition house located on a quiet residential road next door to the main hospital site in Northampton.

The service in Berkeley Close provides 24/7 nursing support for men and women who are recovering from an acquired or traumatic brain injury.

The community-based structure supports patient progress by testing and consolidating their daily living skills, cognition and behavioural management in a safe environment, with the support of a full multidisciplinary team.

For Neelam change is something she struggles with, following her negative experiences in previous hospitals. However, the pathway at St Andrew's means that the clinical team can maintain involvement in her progress. She will retain the same Responsible Clinician and new staff will shadow Elgar staff to understand Neelam's needs prior to her transition.

Neelam says: *"I was thrilled to hear the news that I'll be moving to step down care. I feel ready for it, although I will miss the ward staff terribly as they've been so good to me."*

"But I'm happy. I have a bright future. This is a big moment for me, one that I never thought would ever be possible. This means I'll be able to live more independently, and I'll have more responsibility which is very exciting news for me."