



Case study 2

Tom: where to live after experiencing a stroke

1 Background

Tom is a prominent architect in his early 60s. He had a serious stroke, which affected his ability to speak, and spent a period of time in hospital on the stroke ward.

Before the stroke, Tom and his wife were living separately and in the process of divorcing. His wife was now being placed in a difficult situation: the hospital wanted her to represent his views, which she wasn't willing to do. She wanted to make sure their two young children would be able to see their father, but she didn't want to be in the position of representing his wishes. This led to a difficult relationship between the wife, hospital and social worker.

We were asked to support Tom in his choices about long term accommodation when he left hospital.

2 The case

Tom was a very intelligent man and had written several books. It was extremely frustrating for him not to be able to speak, and to have such difficulty communicating. It was distressing for him not to be able to get his opinion across, and to feel his wishes weren't going to be taken into account. He didn't lack capacity to know where he wanted to live, but he wasn't able to instruct, guide or influence the process.

Our advocate, Nick, worked with him by using cards, symbols, and various other tools to build a rapport and develop a communication system.

From the outset Tom communicated clearly to Nick that he wanted to return to live at his home. However, his social worker thought it would be better for him to be in a more supported environment, and had initially proposed for him to be in a setting that was largely older people with dementia who were not particularly sociable. Nick spoke to Tom, his wife, and others who knew him. He ascertained that Tom was a sociable individual, and this placement would not meet his needs.

Nick worked closely with the other professionals involved, including occupational therapists and speech and language therapists, to make sure the decision about where Tom would live was his own choice and his wishes were at the forefront of any plans. Nick strongly advocated for Tom's wish to live at home, and eventually the social worker agreed the original placement was not in his best interests.

Adaptations were made to the flat so Tom would be able to return home. Nick supported Tom to gather some friends who arranged for people to visit and support him so he could live independently.

Over the following months, Tom, Nick and his friends were able to establish what he could and couldn't do. For example, he was able to buy a ready meal and put it in the oven, but wasn't aware he needed to take it out. Nick supported Tom to understand what kind of support he needed, and arrange this with different agencies. It was a difficult transition, but over time he was more settled.

3 Outcomes

Tom was able to return home to his first floor flat which he loved. As an architect this was especially important to him: with full height, south facing windows, all his models of architect builds, his drawings, art and architecture books around. He was able to start to rebuild his life.

His young children were able to cycle round to see their dad whenever they wanted. And his ex-wife didn't feel pressurised to look after him.

Because of the positive process and outcomes, the hospital team in the stroke unit are now more aware of the advocacy role and actively want advocates to support patients. It's now seen as being just as important to have an advocate present in multi-disciplinary meetings as the different medical professionals.

From initially feeling emotional and frustrated at not being able to communicate easily, there was a marked change in his sense of wellbeing. Our advocate noted his sense of joy returned, he felt confident Nick had his best interests at the forefront and he felt relieved that some normality had resumed.

Being back at home, surrounded by friends, and having a robust support plan meant he was able to lead a more normal life.

Our advocate's assessment of Tom's outcomes

- at the beginning of the case
- at the end of the case

Strongly disagree Neutral Strongly agree

