

Case Study

If In Doubt – Speak Out!

My brother is 48. He has severe autism and a learning disability. He is non-verbal. He spent most of his life in residential care far from our home. Six years ago, I became the 'court appointed deputy' for my brother which made me officially responsible for making decisions on my brother's behalf where he was not able. Until then my parents had been the main link with his residential care home but as they became older (they are both 80 years old), it was time for me to help.

I had been working in the social care sector and involved in disability policy. When I took over responsibility for my brother I also noticed he was on a long list of medications. When I started asking questions about the medications, such as what they were for, how long he had been taking them and why – staff were unhelpful and evasive. In a meeting with the local authority they were resistant to reviewing his medication. But I kept asking.

At the same time, I worked hard to find my brother a more suitable home, closer to family where he would have a better life. In 2012 he moved from residential care to supported living with a new care provider where he had his own flat, just ten minutes from my parents. With this move came a new opportunity to examine the medications he was being given. For example, he was being given anti-depressants and asthma medication but had never had a diagnosis of depression or asthma. He was on anti-psychotic drugs and when I read about the side-effects I could recognise these in him – such as weight gain, sleep problems and drowsiness. He was sleeping a lot during the day for example.

One thing I realised is that my brother's support staff did not feel empowered or knowledgeable enough to ask questions about his medication to medical professionals. So I wrote to his psychiatrist setting out my concerns. He was given an appointment at the local hospital and I attended with him and his support staff to discuss his medications with his psychiatrist. Luckily, as my brother had moved home and county, his psychiatrist was new to his case and was able to look at his medications without any previous connection to administering the drugs in the first place. She agreed that she did not see a need for him to be on most of these drugs. She recognised that historically, many people with autism and learning disabilities were given medications unnecessarily – especially in group care settings and large institutions, to make them easier to 'manage'. However, the issue was that since he had been taking these medications for over 20 years, he could not just be taken off them due to potential risks from withdrawal but over the past few years the doses have been continuously reduced with the aim of him coming completely off them.

The positive impact on my brother's quality of life has been remarkable. Initially his care team were concerned about negative reactions such as increased anxiety and were carefully monitoring and reviewing any behaviour change. But my brother became more alert, active, stopped dribbling continuously, his drowsiness

disappeared, he stopped sleeping all day, his challenging behaviour reduced significantly and he became more engaged.

I find it shocking that he had been prescribed such strong drugs for decades without this ever being questioned. My parents had not been informed or consulted when he was initially put on these drugs. I also found it disappointing that when I did ask questions, care staff were not open to discussion. I was lucky to have experience in social care and learning disability and the skills to be able to challenge people and find support which resulted in a positive change for my brother. But it should not be this way. Too many people are still being given medications today just because they have always been given medications, or because it is more convenient than exploring other options. And too many people that should be speaking up, and asking questions do not feel able to – or just don't know how to.

My top tips are:

- If you are taking medications or support someone who does, make sure you know why
- If you do not know why, ask the medical professional who prescribes the medication to explain why. If you do not understand or do not agree – tell them
- Just because you have been taking medications for a long time doesn't mean to should keep taking them
- It is your right to ask for medication reviews or alternative options to medication. For example, if you are being given medication to manage anxiety, do you and people who support you understand why you might be anxious and what else can be done to manage your anxiety other than drugs?
- If you need help speaking out, there are organisations and experts that can support you.

Endnote:

- For further information about STOMP visit:
<https://www.vodg.org.uk/campaigns/stompcampaign/>