

Jo's story

Context

This case study is written from the perspective of a Registered Care Manager.

Jo moved to our service 18 months ago with complex health and emotional needs. She is blind, nonverbal, with a severe learning disability and eats a pureed diet. When she moved to her new home we wanted to review her entire care needs. She was taking 16 different types of medication for a variety of health and behavioural needs.

The person-centred review which accompanied her did not discuss health needs or medication which we felt were impacting on her ability to communicate and her behaviour.

Action

We felt that her health needs should be thoroughly reviewed and care improved before we could focus on developing her communication and strategies to support her behaviour. Jo was prescribed calorie supplements and several anti-constipation medications; she was also having enemas twice weekly, had 2 epilepsy medications, plus a daily medication and an 'as required' medication to manage her behaviour.

Shortly after Jo arrived I approached the local learning disability team asking for a full suite of referrals – epilepsy, diet, continence, speech and language therapy (for dysphagia support) and psychiatry. We were encouraged to improve Jo's nutrition. She often has a poor appetite so we completed a tailored menu using high nutrition and high calorie homemade food with lots of spices which is her preference, for example porridge, coconut, cinnamon and fruit or scrambled eggs with mashed avocados and paprika. The speech and language therapist advised on preparing food and how staff could best support her during mealtimes.

Another aspect of care was night support. Previously Jo had waking night staff checking on her every half an hour due to epilepsy and incontinence risk. The team thought this was too disruptive for her, so we purchased a night time monitor that measures moisture and movement so she could usually get a good night's sleep.

The psychiatrist wanted a full year of monitoring before looking at Jo's medication. Over the course of the year her general mood improved and there were fewer seizures and behavioural incidents than at her previous home, although she still had times of high anxiety usually lasting for a couple of weeks and then periods of calm for a month or two.

After a year the psychiatrist discontinued the 'as required' medication for behaviour as we had not used it since Jo moved to the service. We found that when she was anxious we could support her in other ways. We also agreed to reduce and discontinue the daily olanzapine over the period of two months. Initially, there was some behaviour that challenged us, but this gradually reduced. Since Jo has

stopped this medication, we have noticed that she opens her eyes more and we think she may have some light perception. She always stops on the stairs where there is a window. She had done this previously, but it is more pronounced now. She seems much more alert.

The next epilepsy appointment reduced then discontinued the daily carbamazepine. Since then there has been no increase in seizures. This has also probably helped Jo feel more alert and we think discontinuing both the olanzapine and the carbamazepine is reducing her constipation. We have seen a significant reduction in the number of enemas she needs.

Many of the issues that Jo arrived at the service with are still evident, such as difficulties with weight, behaviours and seizures, but we are supporting her as a whole person rather than looking at each issue separately. Now there is consistency in her life we are able to develop her support around communication, mobility, relationships and promoting her independence. She is a much happier person.

Conclusion

Overall, we have learnt that services should not treat conditions separately but look at the person as a whole and understand how one thing affects another. Jo no longer uses behaviour medication and all other medication has decreased significantly from 16 different regular medications to two 'as required'.