P writes about her daughter

Parent story

My daughter was attending college three times a week as well as attending a farm once a week and a dance group once a week.

She loved dancing and gymnastics and was very confident when participating in shows, competitions and displays. A few months before onset of symptoms she choreographed her own solo performance at a showcase event for young people with learning disabilities at a major local theatre – a performance widely regarded as outstanding by those who saw it.

She was very sociable and loved attending youth club. She was very organised and liked to be as independent as possible. She always knew where her things were and liked to take good care of them.



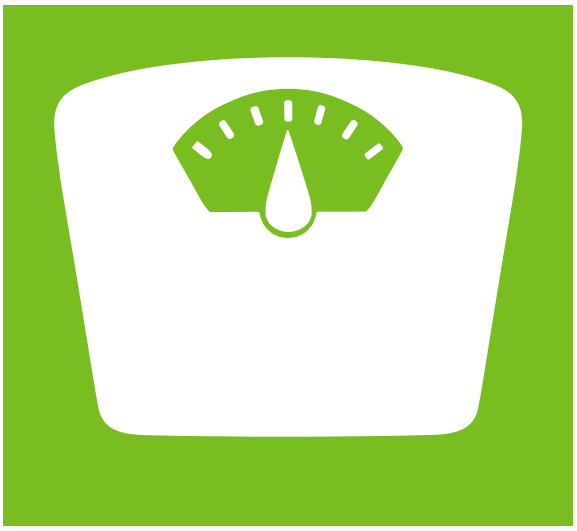
Her understanding of the world and concepts of stranger danger etc were very limited and she didn't really go out independently other than walking to college each day which was just around the corner from our house.

She was mostly independent with her personal hygiene only needing help sometimes. She liked to look her best and enjoyed clothes hair and makeup. She appeared happy, carefree and had a good sense of humour.

What happened

We started to notice changes two years ago when she was 25 years old. Initially, concerns were related to physical health as she complained of palpitations and dizziness, and she had one episode of possible syncope.hortly after this she started to become withdrawn and disengaged. She seemed depressed saying things like 'I don't want to feel like this' and 'I feel scared' but she could not say why. It became apparent that she was losing weight.

At her LD health check in April 2023 weight loss of 7Kg was noted over two months despite eating normally. At times though she was very hyperactive, especially when dancing. Her voice changed and she started to growl when singing or speak with a gruff voice. Bloods were taken at her LD health check, including thyroid, were normal.



She started to become very angry, especially towards us her parents, and she was at times destructive when she became angry or frustrated.

She started to 'grunt' at the end of sentences especially when engaging in self-talk which she was doing more and more.

She became increasingly isolated in her room and during these times she was constantly and energetically dancing – seemingly unable to relax. She struggled much more with conversation often refusing to engage with people who tried to initiate a conversation or even respond to a simple greeting or question. When asked why she was like this she would say 'I didn't know what to say' even though these were situations that she was previously comfortable with. At times she refused to go to college which she previously enjoyed.

At around this time we sought help from her GP and it was felt that cardiac problems needed to be ruled out first so she had a 7 day ECG and an echocardiogram. She also had a reveal device implanted to detect any arrythmias, but the conclusion was that there was no significant cardiac pathology to account for her symptoms.

She was referred to the Learning Disability Team for psychological support and had a nurse assessment. This led to regular visits working on anxiety management with some limited, short term, benefits.



She started to develop 'false memories' about things that had not happened such as accidents that she had had in the past and even assaults. She started to ruminate about her past often asking if she was a good baby and did we love her when she was little.

By September she was exhibiting other physical symptoms such as abnormal posture ('perching' when sitting) and tip toe walking. She became incontinent of urine and faeces at times. She was almost incapable of self-care without help. She became incredibly anxious during a stage dance performance which she struggled to complete because she was trying to do it on tiptoe.

Her GP was contacted again and because we had learned about DSRD she agreed to try treatment with Sertraline (an SSRI) and Lorazepam (because of the catatonic symptoms). The GP also referred her for a CT scan, which was normal, and arranged an LD psychiatric assessment.

She has improved on the medication but is clearly nowhere near the girl she used to be. She is better at self-care and takes pride in preparing (with supervision) her own meals. However, she remains anxious and low in confidence. She is angry at times and isolates herself. She still walks everywhere on tip toe and still grunts during her speech. She can walk on flat feet but becomes angry if asked to do this and says she can't talk if she walks on flat feet.

Her mood can switch in an instant and she reads insults into any suggestion that might help her and becomes angry and uncommunicative. Confidence levels are low, and she struggles to communicate effectively with her peers. There seems to be little 'joy' in her life now and our memories of that confident solo stage performance two years ago seem like a half-remembered dream of a different girl.

Were there any significant changes in your daughter's life before she started to show symptoms?

During the two years prior to symptom onset, she lost both of her paternal grandparents and an uncle. Her brother had moved away from home to university. Her college course changed. She had a strong, but particularly problematic friendship, which became quite difficult for her to understand and manage and subsequently ended as they drifted apart.

Investigations and treatments

A brain CT scan was organised by her GP.

The LD Psychiatrist carried out a dementia questionnaire and thought the probable diagnosis was early onset dementia until we pointed out that her symptoms were variable and that her CT was normal. Subsequently, at her last review, the LD Psychiatrist stated her diagnosis as 'being assessed for DSRD'. However, they had not arranged any further assessments, investigations or tests.



She is prescribed Sertraline (150mg daily) and Lorazepam (0.5mg AM and 1mg in the evening at our request based on a diagnosis of DSRD.

We have since moved to a new area and my daughter saw a locum LD Psychiatrist who was knowledgeable about the condition and he was extremely pleased with the progress that she has made. He felt that she was on the correct medication and did not want to make any changes.

She remains on the same treatment, and I do really feel that she overall continues to improve. She has moved into supported living which has not been easy but she really likes it there and has managed remarkably well.

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