



Helping to support families with assistive technology where there are acute learning disabilities offers such positive benefits for the family as a whole.

We felt very privileged to work closely with Lily and her daughter Emma who was diagnosed with Sanfillippo disease at the age of 4 years. Affected children, generally do not show any signs or symptoms at birth. It is in early childhood that they begin to develop developmental disability and the loss of previously learned skills. Sanfillippo disease is an extremely rare MPS disease which is life limiting and patients usually live into adolescence or early adulthood. Treatment remains largely supportive.



Sanfilippo syndrome type	Approximate incidence	Percentage of cases	Age of onset
A	1 in 100,000 ^[17]	60%	1.5-4
B	1 in 200,000 ^[17]	30%	1-4
C	1 in 1,500,000 ^[17]	4%	3-7
D	1 in 1,000,000 ^[17]	6%	2-6

“My daughter has profound learning disabilities where she is physically restricted. She is unable to operate any tablet or control technology that requires physical literacy. For these reasons, we are very limited to what we can use in our home to help her. Trafford Council gave us access to MYQOL’s interactive system in our home and it was amazing to see the difference it made for her.

It was easy to setup and we found:

- She has a lot of anxiety and agitation and MYQOL was immediately able to calm her. I put on several features that really helped to reduce her anxiety including the lily garden music, the relaxing pond sensory and it was so tranquil. She frequently fell asleep listening to the calming sounds and watching the dolphins on the ceiling.***
- When she is in her bed, I was now able to film my garden outside along with the dogs and bring these to life on the ceiling using MYQOL’s projector. Prior to this we were limited to using the TV.***
- We also used some of the LD games which she liked including the jigsaw”***

