

FEEDBACK SOUP

Northwick is a very special bear. He lives with a boy called Frank and his family. Both Northwick and Frank have nystagmus.

“I am NOT stropopy!” said Frank loudly (and somewhat stropopy) while accidentally knocking over his glass of water. Frank’s mother and father stayed calm. They were not surprised. Nor was Northwick. It was Thursday evening, probably the worst time of the week for Frank. Ever since Frank had started school, there was a good chance that Thursday Evenings would be Stropopy Evenings.

It had taken Frank’s parents a few months to spot the Stropopy Thursday Evenings pattern. At first they worried about it. Was he being bullied? Was it something he’d eaten? What was it about Thursdays? Then they spoke to Ms Strawberry, the support teacher who kept an eye on Frank’s eyes in school.

Ms Strawberry knew all about Stropopy Evenings. She said it was a nystagmus thing and was due to tiredness. People often didn’t realise how tiring it was to have nystagmus. Nor did they realise how much worse tiredness made nystagmus in both children and adults.

One thing after another

In Frank’s case, suggested Ms Strawberry, by Thursday he was exhausted after four days of doing things children with ordinary vision found easy. Looking at the white board, finding things in the classroom, avoiding other children in the corridors – all these tasks were much more difficult and tiring for Frank.

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Even magnifiers and other low vision aids – which could be quite helpful – took their toll, she said. “Just try looking through a monocular for 15 minutes and see what it does to your eyes,” Ms Strawberry had told Frank’s parents.

But what many people didn’t realise about nystagmus, she added, was that it acted like a feedback loop. The tired Frank got, the worse his nystagmus got. And the worse his nystagmus got, the more tired he got.

Ms Strawberry then asked if Frank seemed clumsier when he was tired and stropy. Frank’s parents looked at each other and nodded. They both had a lot to learn about nystagmus they realised.



Pennies from heaven

By this time, pennies weren't so much dropping as raining down from above on Frank's parents. They had noticed Frank's eyes flickering more as the week wore on. They had noticed that he started the week happy and full of energy, but flagged and sagged day by day.

And yes Frank was definitely more likely to knock things over or bump into furniture, and even people, by the time Stroppy Thursday arrived.

The doctors had mentioned that nystagmus would make Frank tired. But no-one had warned his parents about mood swings. And now Frank's mother thought about it, she realised that Stroppy Thursdays all but vanished during the school holidays.

Timetable tweaks

Ms Strawberry said they should devise a plan so that Frank didn't get so tired and his nystagmus didn't get so bad that it made him stroppy. She would talk to the teachers in Frank's school, agree some tweaks to the timetable and make sure he could have a rest now and again.

Most children with nystagmus got really tired after lunch, said Ms Strawberry, although everyone was different. One big part of the plan was talking to Frank so that he could ask his teacher for a rest whenever he needed one. And that's what Frank's parents were doing this Thursday evening.

"Often just closing your eyes for five minutes is all you need, Frank." His father said. "The important thing is to have a rest as soon as you feel tired. Otherwise the nystagmus just gets worse and you won't be able to see what you're doing anyway."

Frank listened carefully, as did Northwick. As Frank listened it all began to make sense. He was slowly coming to realise that nystagmus affected him in ways he'd never thought of before. He did feel tired in school, especially in the early afternoon. Unlike most of his friends who bounced back into the classroom after lunch.

Frozen screen

Frank liked the idea of being allowed to close his eyes for a few minutes when it got hard to see. He already knew that staring into space helped calm his eyes down when the world got very jittery. But once or twice when he had shut his eyes in school he had been told off for not paying attention. Now he had permission to rest his eyes. A rest would be a big help, especially with his null zone.

Recently Frank had noticed that his null zone didn't always work. Even turning his head more didn't make the world still. And now he came to think of it, he was often tired when his null zone stopped working. Being able to rest his eyes for a few minutes would, he hoped, reset his null zone so that he could see things again.

Northwick, who almost always struggled to stay awake in the evening, yawned. When he had finished yawning he said that, just like Frank, resting his eyes often stopped the world jumping around, adding: "It's probably a bit like turning a phone or laptop off and then on again when the screen freezes."

Frank's parents looked very impressed. And Frank's father said that Northwick was sometimes a very wise bear.

"Thank you," said Northwick, "but I do have one question for you. I may have nodded off a few minutes ago, but I'm sure I heard someone talking about feedback soup. What exactly is feedback soup? I've never heard of it before, but it sounds quite tasty."