

MUFFLED MEANINGS

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

For Frank and Northwick there was only one place you could write your letter to Father Christmas: Grandpa's living room. The room looked, sounded, smelled, tasted and felt like Christmas. The floor to ceiling tree was festooned with bells and baubles. Decorations dipped and dived from corner to crevice. Best of all for Frank were the twinkling, magical, mesmerising lights winding through the house.

Northwick's favourites were the smells: the clean outdoors smell of the Christmas tree, the warm smell of the fire and of course the spicy smell of cakes. It all made Grandpa's living room the perfect place to write long lists to Santa and dream about the presents you'd like for Christmas.

Which is exactly what Frank and Northwick were doing this dark December afternoon. Grandpa always helped them write to Santa. He was usually very good at suggesting presents they wanted. But this year Grandpa said something that took Frank by surprise. "That's not a present!" Frank almost shouted through a muffled mouthful of marzipan.



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Big bad words

"I didn't say it was a present," said Grandpa. "It just happens that it's nearly Christmas and this is something I can do for you and Northwick -- in fact for everyone who has nystagmus. I'm sure you'll still get presents from Father Christmas."

"So," said Northwick, briefly putting down the half a mince pie he hadn't yet eaten, "you want us to think of nice, simple words for anything to do with nystagmus. Is that right?"

Grandpa took a sizeable swig of tea from his Nystagmus Network mug and moved his feet closer to the log fire. "Yes. You see, I remember what you said about how old people like me don't feel comfortable talking about nystagmus. I've been thinking about that a lot. And, when we do talk about nystagmus we mostly use big medical words or words like *problem* and *disability*."

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Grandpa went on: "I've persuaded a journalist friend to make a video about nystagmus. It will focus on what you can do instead of what you can't do. It will avoid words like **problem** and **wobbly**. The video will go on the Internet where lots of people will see it. And, hopefully they will start talking about nystagmus in a nicer, clearer way. Just like you and Frank want."

Hospital words

Frank brushed crumbs off his fingers and on to his plate. He sat up, said he liked Grandpa's idea and began to write. "First of all," he said, "most of the time let's say **flickering eyes** instead of nystagmus. It's OK for doctors and hospital people to say nystagmus because they know what it means. But no-one in school uses the word."

Northwick nodded. "And flickering eyes is much better than **wobbly eyes**. Somehow wobbly isn't a very nice word. Stomachs wobble," he said, "not eyes."

"Then there's **suffer**," said Frank, almost spitting the word out. "That sounds like I'm in pain all the time. I don't think I suffer with nystagmus. It's just the way my eyes are. I simply tell people I **have** nystagmus."

Northwick added that it didn't help to use words like **wrong** and **problem** either. "It makes me sad when people ask: What's wrong with your eyes? Or does he have a problem seeing things? It's better to say that I see differently from most other people and bears."

Frank agreed that some of the things people said about nystagmus made him sad too. "Another word I really dislike," he said, "is **abnormal**. It's horrible when the doctors say I have abnormal head posture, because of my null zone. Why not say 'the best position for seeing' instead? That sounds much more positive."

Northwick said he didn't like the phrase **null zone**, adding: "No-one knows what it means anyway. I always have to explain it and say there's one direction where my eyes feel most comfortable and that's where I see best."

Safe and cosy

Grandpa said Frank and Northwick had been very helpful, but now it was time to return to enjoying the Magic of Christmas. Hearing those words seemed to Frank to change everything in the room. He became aware of the hushed shadows around the fairy lights and the safe and cosy flames in the fireplace.

Northwick was similarly smitten by the smells of treats and tree and tangerines. He was nearly nodding off when Grandpa said, in what to Northwick seemed little more than a whisper: "Let's finish those Christmas present lists. That's what we're here for. And maybe we could have a bit more cake too."