

FRANK BEATS THE BUTTERFLIES

"That's another problem," said Frank, "I can't tell which one of you is talking to me right now." This was not surprising. Frank was in a big hospital room full of grown-ups he didn't know, apart from Amy. They were all asking him questions. That made him nervous at first, although he was quite enjoying being the centre of attention now.

Amy was an orthoptist, like most of the people in the room. She saw Frank when he had an eye appointment at the hospital. It was Amy's idea for Frank to come and tell her colleagues what it was like to have nystagmus. The orthoptists saw children with nystagmus every day, but they still had lots of questions for Frank about living with wobbly eyes.

"Thank you Frank," said Amy, "that's something else to remember with nystagmus patients. Scanning is really hard for them. They can't always work out who is talking to them, especially in a busy place, no matter how near they are to you. So, if you have a question for Frank, please stand up and tell him which part of the room you're in. Anything else Frank?"

Happy eyes

Frank didn't need much encouragement from Amy now. The butterflies in his belly had given up and he felt quite relaxed talking to so many adults. That meant his eyes weren't jumping about so much either. So he explained how the happier he was, the easier it was to see.

Amy had sat down with Frank earlier and helped him to write a list of things to talk about. The list was on cards in very big writing, so that Frank

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could see the words even if his nystagmus was bad. He had already told his audience of orthoptists about needing more time to see. About how it was hard to see fast moving things or people. About how the wobble got worse if he was tired or anxious or not very well.

One of Amy's colleagues asked Frank if he ever saw the world moving. "Usually only when it's time for bed, or if people make fun of me, or something like that," replied Frank. Then he remembered something else: "or if I try to look out of the left side of my eyes. That feels really uncomfortable. Nothing stays still on that side, so I don't even think about looking there."

Amy said that was another helpful observation. Frank wasn't sure what an observation was. But Amy said it was helpful, so that must be good.

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She explained that the world moved on the left because Frank's null point was on the right. That was the direction where his eyes moved least and so where it was most comfortable for him to see.

Ordinarily different

Frank carried on talking about the things on his list: lighting and glare, good contrast (big black letters on a white background for instance), how he sometimes tripped or bumped into things and even how he needed to get closer than people with ordinary vision to see things.

When Frank got to his final card, he hesitated. Amy smiled at him and said encouragingly: "Go on, Frank. Tell everyone. This is probably the most important thing you've taught me about nystagmus."

"Well," said Frank slowly. "When I was very little, I didn't worry about my eyes being different. Now I do and that's not nice. Yes I need a bit of help sometimes because I don't see so well. But everyone is different in one way or another. I'm just ordinarily different really."