

Medical Scenarios

You were invited to your friend's house for a sleepover on Friday, but you're kind of nervous about going because some of the other people invited always ask you about your brother, Elijah, who has Down syndrome. One question they recently asked you was if you would have a kid with Down syndrome when you get older. How could you respond?

Pretend you're the parent of two children: one has Down syndrome and one does not:

While shopping in the grocery store with your younger son, Alex, you ask him if there was anything about his older brother, Neal, who has Down syndrome, that bothers him. He asks, "Will he always stick out his tongue?" How would you approach the situation?

Today in science class you learned that people with Down syndrome have many medical complications and can get Alzheimer's when they get older. You're now worried about how long your sister with Down syndrome will live. What can you do about your fears?

Here are some notes on these questions:

- To answer the question about heritability of Down syndrome for the sibling, refer to the "Topics" section of this site that discusses this very question!
- Sometimes people with Down syndrome will have protruding tongues due to their sometimes having larger tongues or smaller upper jaws, as well as the low muscle tone necessary to control the tongue. As your sibling gets older and completes more speech and physical therapy, they will gain better control over their tongue. Maybe you should also talk about why this makes the brother or sister uncomfortable—are they embarrassed? It's okay to be embarrassed; discuss how to deal with others staring by checking out the "Topics" section of this site.
 - For more information on this topic, check out Dr. Brian Sktoko's and Sue Levine's book, *Fasten your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*, Chapter 1: Gearing Up to Go: getting the facts about Down syndrome, page 14!
- People with Down syndrome are at an increased risk of developing Alzheimer's as they get older. You can make sure that your sibling is seeing a trusted physician regularly to maintain their health and address any concerns you, your sibling, and family have.