

Scenario 4

A Heartfelt Quandary

Grace has had a hard time, to say the least. Eighteen months ago her 34 year old brother died mysteriously in his sleep, and just six months ago a young cousin collapsed and died at a rock concert. Grace has very few memories of her father, who died suddenly when she was just five years old. All three deaths were caused by heart attacks.

Grace's medical and family history indicated that she might be at risk of Hypertrophic Cardiomyopathy. After much deliberation she decided to undergo genetic testing. She was recently tested and found to have a gene change (mutation) in the MYH7 gene associated with Hypertrophic Cardiomyopathy. While she has taken her doctor's advice to modify her lifestyle, including avoiding competitive sports and strenuous exercise, she plans to keep up her job as the local school bus driver.

"There's no way I'm telling my boss about this," Grace said to her doctor. "My husband left me recently after his business went bankrupt and it's up to me to support my two kids. My boss would have me out the door in a flash if he thought there was something wrong with me, and then what would I do? I don't know how to do anything else. I'm taking care of myself, I'm a vegetarian and I do yoga twice a week. That's more than I can say for some of the other drivers. They're fat and smoke like chimneys; they'll drop dead before me."

"Mr Moral Quandary works as the receptionist for Grace's doctor. He is a member of school council, and his two children aged 14 and 16 travels on the local school bus. He is aware of Grace's test results and plans to inform school council of Grace's genetic risk status.

"It's a question of the broader interests of the community being more important than Grace's right to privacy. My children travel on that bus and I would be remiss in my duties if I ignored the fact that she is endangering our community's most precious assets," he said.

Mr Quandary's plans have enraged his wife, Justice Quandary, who is a prominent civil rights activist. "Grace will suffer discrimination if you reveal her genetic status to the school committee", she argued. "I want our children to remain on the bus to demonstrate the importance of civil freedom. Plus, how do you know what the test results mean? Grace may be at no more risk of dropping dead than you or I," she said to her ex-husband.

Issue

What would you do if you were in Mr Quandary's position? Would you inform school council, yes or no?

Your response should include the pros and cons of Mr Quandary informing school council.

Questions

Here are some questions for you to consider in responding to the issue.

1. Who has the right to know?
2. Examine all the points of view.
3. How would you feel if you were a student on the bus?
4. Would parent concern be valid?
5. Who is at risk? Are there any other potential sources of risk?
6. Should employees disclose information about 'potential' health risks?
7. Have you examined the four principles of bioethics?