Speech By

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ADJOURNMENT

Motor Neurone Disease

Mr J KELLY (Greenslopes—ALP) (9.21 pm): From 6 pm last night to 6 pm tonight I participated in 'Quiet Please for MND and Me'. I stayed silent with just a few slips, using only an app to communicate—and it was incredibly hard. With the exception of Hansard reporters, we all speak and think much faster than we type. Even though it was only for 24 hours, I did find myself getting a bit lonely at times. I changed my behaviour and avoided some events because it was just too hard to be in a group where you are the only one not able to speak. Ordering meals and asking for help was slow and difficult—and it felt weird. I really missed saying good night and good morning to my wife and daughters. This was tough for me today, but many people who live with motor neurone disease face this reality every single day.

This morning I met Gina and Leanne. Gina is related to my great friend Grace Grace and, like Grace, she could talk. She could not move any other parts of her body, but this retired teacher has learned how to use communication devices and has illustrated kids' books. Leanne was a personal trainer and she had lots of tips for the member for Miller, who showed up in his cycling gear. She uses communication devices for all of her interactions. We communicated in the same manner and at the same speed. Leanne was the only person I had an equal communication with over the last 24 hours and, because of this, I kept gravitating back to Leanne to speak with her on equal terms. She is also an author and has written a motivational book.

The MND and Me Foundation was started in 2010 by Scott Sullivan to raise money in his community for research and support services. I particularly want to thank Easts Rugby Union and the other sporting clubs that have so actively supported this group. Scott has passed away but his legacy lives on. This organisation has literally raised millions and millions of dollars for research.

Every single day in Australia two people are diagnosed with motor neurone disease and two people lose their lives to it. MND is a devastating terminal disease that takes away movement, independence and, for many, the ability to speak. The MND and Me Foundation, a proud Queensland and Coorparoo charity, is working tirelessly to ensure no Queenslander faces MND alone. Through its programs it provides the right solutions at the right time at no cost.

One of its most impactful programs is Communication Connect, a program that provides fully funded communication devices such as iPads with text-to-speech apps, eye-gaze technology and NeuroNode devices. These devices can cost over $20,000. If I learned anything today, I learned how crucial these devices are for people with MND. I want to thank everyone across the parliament for their support, particularly Mr Speaker, the health minister, the shadow health minister and Steven Miles, the Leader of the Opposition. I particularly want to thank the Manager of Opposition Business and the shadow whip for not just allowing me to do it but supporting it. I want to thank the MND and Me Foundation, particularly Cheyenne. I really want to thank Gina and Leanne. You two are amazing and special beyond belief. You will always have my support for people who are living with MND.

Mr SPEAKER: It is a truly great cause.