

**MOTOR NEURONE DISEASE ASSOCIATION OF WESTERN AUSTRALIA**

*Statement*

**HON HELEN MORTON (East Metropolitan — Minister for Disability Services)** [9.52 pm]: Last week, from 17 to 20 October, the Motor Neurone Disease Association of Western Australia held its first Motor Neurone Disease Drive. This event was a four-day 1 500-kilometre drive from Perth to Carnarvon to raise funds for the association and to raise awareness of the disease. I bring this event to members' attention today to remind the house of the very important work undertaken by the Motor Neurone Disease Association of WA and to commend it for initiating this new fundraising event. About 20 vehicles and 100 people took part in the drive event, with drivers and their crews having to raise \$5 000 each before they could set off and take part. The convoy included Australian sporting legends, including former test cricket captain Kim Hughes and AFL player and coach Ken Judge. Along the way they explored the WA coast. They visited Cervantes, Geraldton and Kalbarri and other towns where entertainment and fun events had been arranged. The journey ended with a celebration in Carnarvon. All the fun they had literally paid off. The four-day drive raised about \$200 000 for the Motor Neurone Disease Association. These funds will be absolutely invaluable in assisting the association to continue its work to raise awareness of motor neurone disease and to support families affected by the disease.

In a slightly arm's length way, I am one of those families. My only sister, Barbara, was diagnosed with motor neurone disease about two years ago. She was working as a phlebotomist. For those who do not know what that is, it is someone who takes blood. She knew that something was wrong; she had lost strength in her left hand and had lost the fine motor skills to enable her to do that job. I had noticed over a period of time while she was talking to me that her speech had slowed and she had started to slur a bit. All of that was before she was finally diagnosed with motor neurone disease. Given the very poor prognosis associated with motor neurone disease, her husband resigned from his job. He was a miner-truck driver kind of guy, and he became her full-time carer. My sister and her husband have been greatly supported by the Motor Neurone Disease Association of Western Australia. Her husband now does most things for my sister. I visited her last weekend, and she was talking about what it was like to have her husband do her hair and how blokes just do not know how to blow-dry hair properly and put it in the right place. He has now also learnt how to put on her make-up. I thought it was phenomenal for this bloody great big miner-truckie to learn how to do that. Am I not allowed to say that?

**Hon Peter Collier:** You already did!

**Hon HELEN MORTON:** Anyway, I thought it was amazing that this big bloke was providing that level of care to my sister.

My sister was a great cook, and she loves entertaining, which is still happening, although of course others do the cooking, and her husband is nowhere near the sort of cook that she was. My sister has not lost too much weight, which is a good thing, because apparently that is one of the significant signs of progression of this disease; but then she can still swallow, and it will not be long before she will not be able to do that, and that is when people need to use artificial feeding processes.

A few months ago, my sister and her husband had a gathering at their place of fellow people with motor neurone disease, and their families, from the northern suburbs. That was organised by the Motor Neurone Disease Association of Western Australia. At that gathering they learnt about and discussed all they need to know about the advanced care directives that most of these people will eventually make use of.

For those people who do not know much about motor neurone disease, it is a degenerative disease that affects the motor cells and results in significant and very progressive muscle weakness and paralysis, as well as impaired speaking, swallowing and breathing. There is no cure for this disease. There is no survival rate. This is a terminal disease. The average length of life expectancy at the time of diagnosis is just over two years, or 27 months. So this is a very rapid disease that people go through. I am sorry; I really wanted this to be about the association.

The Motor Neurone Disease Association is a not-for-profit organisation committed to providing quality support and equipment for people living with motor neurone disease and their families. The association provides a comprehensive care advisory service that is partially funded by the Department of Health, as well as education and networking services and supports for healthcare professionals. The association relies upon fundraising and community support to continue the crucial work that it does to increase public awareness of the disease. I congratulate the association for the hard work that it did to arrange last week's Perth to Carnarvon drive event, and thank the supporters for their contribution to the massive fundraising achievements of that week. The outcomes of last week will enable the association to continue to provide support for families and hopefully some time into the future some kind of breakthrough in treatment for people with this disease.