

MOTOR NEURONE DISEASE AWARENESS WEEK

Statement

HON MATT BENSON-LIDHOLM (South West) [9.49 pm]: I rise to make a brief statement to the house about Motor Neurone Disease Awareness Week, which commenced yesterday with a function at Government House. Motor neurone disease has received some sort of profile during the past week with the sad passing of the artist Pro Hart. Before I commence to speak on the issue, I remind members of exactly what is motor neurone disease. It is a rare, progressive, neurodegenerative disease that attacks the upper and lower motor neurones. Degeneration results in weakness and wasting of muscles, causing loss of mobility in limbs and difficulties with speech, swallowing and breathing. The muscles are the first affected. At the same time the brain is completely switched on, as are kidney and bowel functions. Life, however, for sufferers is quite miserable, particularly in the advanced stage, which might occur between five months and five years or even more. I am reliably informed that six in every 100 000 people in Australia are affected by motor neurone disease, most being more than 50 years of age. However, I am also reliably informed that the age of sufferers is going down. As members will appreciate, the impact on families of caring for someone with motor neurone disease is enormous, especially on older helpers. Money and resources are always an issue, likewise time, although it is very difficult sometimes to know exactly when people need particular resources or help. I am informed that on certain occasions mechanical wheelchairs are ordered for sufferers but by the time they arrive they need an electronic machine; sadly, by the time the electronic machine arrives, many are deceased. The Motor Neurone Disease Association of WA works hard to assist those affected by the disease and their families. It is a registered charity and support organisation and is always seeking help as more and more people over the years are diagnosed. The Motor Neurone Disease Association itself has grown to provide a comprehensive care advisory service but, as members will appreciate, it is heavily reliant on donations and grants, and will continue to be so reliant as demand increases for its services. Motor Neurone Disease Awareness Week is launched every year to educate the public; and, dare I say it, members of Parliament are not excluded. I am sure that with improved awareness, funding, which is of critical concern at all levels, will improve. We should remember also that sufferers cannot speak for themselves. Both they and their families need understanding from the community, and I am sure that if that occurs, assistance, support, funding and so on will become an imperative in our society. I acknowledge the Motor Neurone Disease Association of WA and its staff, the volunteers and people who live with motor neurone disease. They are working hard and they deserve acknowledgment for their endeavours during this particular week, and I commend the charity to all members of this house.

House adjourned at 9.54 pm
