




Speech by
Ian Kaye

MEMBER FOR GREENSLOPES

Hansard Thursday, 1 November 2012

MOTOR NEURONE DISEASE

 **Mr KAYE** (Greenslopes—LNP) (3.44 pm): Did members know that almost 300 Queenslanders have been given a death sentence? These Queenslanders have been diagnosed with motor neurone disease, MND, and their life expectancy is between two and five years after diagnosis. That is right—no chemo, no radiotherapy, no stem cell transplant, no hope; just an expectation that their life will come to an end much earlier than they or their family anticipated. Prior to their passing they will lose control of the movement of voluntary muscles, including all the muscles of their arms, legs, back and neck and of speech, swallowing and breathing.

MND does not discriminate. It can affect anyone at any time, although the majority of cases involve adults over 50 years of age. MND may start its ravaging effects in any part of the body and progressively move to other functions at any given time. People cannot plan for its progress. It just has to be managed on a day-to-day basis as it progressively leaves people unable to perform basic muscular functions which we all take for granted. Dressing, walking, showering, toileting all become tasks which require intervention from carers and families.

Loss of the ability to swallow needs to be overcome by the insertion of a peg to facilitate bodily nourishment. For the loss of speech we have seen the introduction of computerised devices such as the iPad, but this may be useless as the use of their hands and fingers may have been lost. Loss of leg muscles of course leads to being wheelchair bound. In the majority of cases, MND does not affect the senses, intellect or memory so one can only imagine the frustration of not only knowing that they are living on borrowed time but also that until they do pass they will become an ever-increasing burden on those closest to them and those they love most, as they rely on them to maintain an acceptable quality of life.

Queenslander Scott Sullivan, aged 40 and himself an MND patient for 2½ years, has committed himself to raising awareness of this disease in anticipation of raising significant funds for MND research. One can only look on in wonderment at what Scott has achieved in this small amount of time. The *Courier-Mail* article of Saturday, 27 October is testament to this outstanding and inspirational individual. I have met with Scott on a couple of occasions and his courage and determination are an example for all. I sincerely congratulate Scott on his strength and determination in his quest to raise awareness of this disease.

The MND Association of Queensland, led by Hedley Lockyer, which celebrates its 30th anniversary next year, is likewise committed to raising MND awareness and raising funds to assist the national research effort through the MND Research Institute of Australia and also to assist with patient care through the provision of education, coordination of allied health professionals and the provision of expensive specialised equipment to facilitate all bodily functions. The MND associations want everyone in Queensland to know what motor neurone disease is. They want to establish a Queensland MND centre which will become the focal point for service delivery to MND patients. They want to make sure that every MND patient in Queensland gets the best possible care in a timely manner so as to improve their quality of life.

I am determined to assist Scott and his associated organisations to raise awareness within government and the community alike of those suffering this terrible disease that unfortunately is a death sentence. People can get involved by registering on the MND & Me website for the Million Metres for MND Swim on 2 December 2012 at the Langlands Park pool or the Yeronga pool to raise money for this worthwhile cause.