

MOTOR NEURONE DISEASE ASSOCIATION OF WESTERN AUSTRALIA

Statement

Hon Helen Morton: Don't look at your notes.

HON SALLY TALBOT (South West) [10.00 pm]: It is all right—I will not be running my finger along mine!

As part of my new portfolio responsibilities, in the past few weeks I have undertaken a bit of a whirlwind tour of the major stakeholders. I am sure the minister will agree with me when I say that I feel actually quite privileged to be working in an area in which the stakeholders are such an inspiring group of people with quite overwhelming commitments to help people who are amongst the most disadvantaged in our community—people who often would not have a voice if it were not for the groups, organisations and individuals who speak up for them.

One day in the past couple of weeks I went down to The Niche in Nedlands, which is actually part of the Queen Elizabeth II Medical Centre complex, which looks a bit like a building site at the moment. The Niche is actually on Aberdare Road, and I had not seen it before. I have driven past it dozens and dozens of times, but I have never actually noticed that it is quite a substantial freestanding building that is divided into half; one half is the independent living centre and the other provides accommodation for groups dealing with neurological diseases.

My appointment was actually with Suresh Rajan, who has the role of director of the Epilepsy Association of Western Australia and is also president of the National Ethnic Disability Alliance; he is a pretty influential person. I am sure many honourable members have come across Suresh wearing one of his many, many hats; he is a very active and lively contributor to our community in Western Australia.

I had a most interesting chat with Suresh. I refer members who perhaps have not caught up with this yet to Suresh's latest platform, which is an online journal called *The Stringer*. I am now on his mailing list, and he contributes very regularly to the online journal and it is well worth having a look at. He has written some very, very good pieces, but in following his contributions I am also picking up a number of other quite substantial contributions to the debate about all sorts of aspects of politics and social policy in Western Australia. I might add that his latest piece, which he sent me last night, is about ethnic representation in our cricket teams.

After my chat with Suresh I had a bit of extra time, so he took me on a bit of a tour of all the other organisations that occupy that half of The Niche. In a short period of time I met the people from Parkinson's Western Australia, and of course we had a chat about the question I asked in the house recently about community physiotherapy services. We felt as though we already knew each other, and that was most interesting. I also met the people from Cystic Fibrosis Western Australia. Also, just in the corridor, coming back from lunch, I had the fortune to bump into Kathy McCoy, who is the executive director of the Neurological Council of WA. I shall be going back to The Niche in the very near future to have a more extended conversation with Kathy and some of her colleagues about the National Disability Insurance Scheme and other developments in the provision of disability support services.

I was also introduced to Fionnuala Franey, who is in the office of the Motor Neurone Disease Association of Western Australia, and that is really the focus of what I wanted to say tonight. I got an email from Fionnuala the other day, pointing out to me that the main objective of the Motor Neurone Disease Association of Western Australia is to raise public awareness about the disease. Many members will remember that we have already worn our blue cornflowers this year. But I did want to take this opportunity to point out that on 21 June, which of course is the winter solstice, there is a global day to mark awareness of motor neurone disease. In Western Australia on that day, the Motor Neurone Disease Association of Western Australia will be hosting a global day lunch at Carilley Estate winery for its members who are either living with motor neurone disease or are the carers and families of people with motor neurone disease. I did promise that I would mention that in this place to alert all members to that event.

Hon Helen Morton: Where did you say that was?

Hon SALLY TALBOT: It is on 21 June, at Carilley Estate. I will give the minister the details—glad to be of service, minister. I do recommend that honourable members who have an interest in this area go to the website about this global day, because it lists all the activities that are recommended for people who want to play their own small part in raising awareness.

I was particularly interested in the activities of this group, for a couple of reasons. The first, as I pointed out to Fionnuala, is that my mother suffered from a rare neurological condition called PSP, or progressive supranuclear palsy, so I have had some experience of having a close family member who has a disease that nobody knows anything about. When I say a disease that nobody knows anything about, it is exactly the same for motor neurone disease. When someone is suffering from one of these relatively rare conditions and needs medical treatment, for

example, either from a general practitioner or as an inpatient, most of the staff—the nurses and some of the junior doctors, and, indeed, some of the specialists—will never have treated anyone with this condition before. So that makes life even more complicated than it normally would be for a person who is trying to care for someone who is pretty sick.

The second reason is an experience that I had recently when I was with a close family member in hospital. It was actually my husband, who had had a routine maintenance procedure on his back, and because the procedure had been done late in the day, they wanted to keep him in hospital overnight until everything was functioning again. He was sharing a room with a chap whom he had obviously never met before, and this man was given the diagnosis of motor neurone disease while we were in the room with him. That was an awful thing to see. There is not much privacy in these places, so we effectively went through about 18 hours when this poor person was trying to come to terms with the diagnosis and they were trying to get his family to come in from the country.

So when Fionnuala wrote to me the other day to ask me whether I would do whatever I could to raise awareness of this disease, I undertook to draw the attention of honourable members to the fact that this group exists at The Niche. I am sure they would be delighted if anyone wanted to make contact with them, because they work very, very hard at just making people more aware of the condition. We would all have constituents who have some experience of the disease, either themselves or from family members. So I urge people to go to the website and look at what will be happening on the global day and generally try to spread the word.

One of the things that Fionnuala was telling me is that because motor neurone disease is a particularly catastrophic thing to happen to a human body, these people have very, very high care needs. It is also, of course, an extremely intense experience for family members to go through, yet it is one of the hardest conditions for which to find respite care. Many facilities will not take people with motor neurone disease; or, if they do, they will take only one person at a time. So people who are going through an extraordinarily stressful and upsetting experience often find that they cannot even get the respite that carers of people with other conditions are able to get. Fionnuala tells me that the association also helps people find suitable long-term placements when they cannot stay in their own home—although it is a reassuring, but I suppose sad, piece of data to find that in Western Australia, more motor neurone disease sufferers are able to spend their last days in their own home than is the case in any other Australian state.

This small group does a remarkably good job, and I am very pleased to play my part in helping to raise awareness of this disease.

House adjourned at 10.10 pm
