

Rodney Harris OAM



Former CEO of Motor Neurone Disease Association of Victoria (MND Victoria), Rodney Harris OAM, has been instrumental in helping those living with MND access palliative care services.

His impact on the palliative care sector has been formally honored a number of times; he is a Palliative Care Victoria Life Member and was also awarded an Order of Australia Medal for his work in expanding access to palliative care for people with life threatening illnesses, and especially those with MND.

Rod's involvement in palliative care commenced in the early 90's, when his wife started working in the sector, however he describes himself as "very much a bystander" until he became the CEO of MND Victoria.

"I started as the CEO in 1993 and I was stunned to find out that people with MND were not accessing the

benefits of palliative care, so I made it my mission to try and change that."

"The first step was getting Palliative Care Victoria to accept MND Victoria as an associate member, then a full member. I also joined the PCV board to represent non-cancer diagnoses."

"I made it my mission to ensure palliative care was available to anyone who wanted it and needed it."

For Rod, creating access to palliative care for MND patients was integral, as it could allow them to live as well as they could for as long as they could, so he worked tirelessly to make it happen.

“In 2007, we did a research project with the Department of Health and Community Service to understand why people with MND were under represented in palliative care services.

“We found that palliative care staff lacked confidence and knowledge of MND. They had very limited experience of the disease and there was no palliative care focused training for MND. We also found that there wasn’t any funding to be able to provide this kind of dedicated training or support.”

“While the results weren’t pretty, the research project recommended substantial change when it came to how people with MND were supported.”

“We got funding to create a position in each palliative care consortium to be the go to person for staff to get information about MND. A training program was established to assist palliative care workers to train other staff on how to approach MND patients. Finally, we created top up funding, which could be used for any additional costs of supporting someone with MND.”

“In the first year after the project was launched, use of palliative care services by those with MND went from 40 clients to 80 – a 100% increase.”

“Patients don’t necessarily need access to intense nursing, but they do need support – support from volunteers, counselling and allied health services...”

It is clear that Rod’s passion for advocating for those with MND has never wavered, despite a number of challenges and differing opinions along the way.

“I definitely ruffled some feathers back then, because I knew palliative care should have been accessed by more people. In the 90’s, it was still all about cancer and pain management. Now, palliative care is available to all people with life limiting illnesses, and I think MND Victoria played a significant role in that.”

“Right at the start, we participated in advocacy with the State Government to try and enhance funding for palliative care in Victoria. Further down the track, I was elected to the Palliative Care Australia board.”

“This advocacy also extended into the Voluntary Assisted Dying (VAD) debate. As an organisation, MND Victoria declared it neither supported nor opposed VAD, however, we did make sure that legislation did not discriminate against people with MND or any other disability who wished to use the legislation. I’m pleased that, as an organisation, we were able to do that.”

Rod summarises his achievements across the years in the best way; “individually, we play a very small part in the world, so you need to do the best you can to have impact.”