

Remembering one of Australia's remarkable women of epilepsy

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• Dr Rosemary Panelli

Rosemary Panelli's professional working life began as a registered nurse. Like many young women who became mothers in the 1970s she balanced nursing and a working life with running a home, eventually taking a part time job with the Arthritis Foundation of Victoria, which was her introduction to work within the community service welfare sector.

She also developed a love of gardening and horticulture and had an almost encyclopedic knowledge of plants, which led to her finding work for a time in a plant nursery.

Then one day she came across a newspaper ad for a person who would like to work with, support and expand the role of volunteers at the Epilepsy Foundation of Victoria.

The Epilepsy Foundation's founders were volunteers, a community of concerned families living with epilepsy, led by a remarkable woman called Mary Davies. They had staffed it and organized themselves into auxiliaries across the state to spread its reach and to help fund it. Sadly, by the mid 1990s the auxiliaries had disappeared.

At the time Rosey joined the Foundation the volunteer base had been reduced to a small number of women who were working for the Foundation at the Foundation's one and only opportunity shop in Kew, along with a small number of people who helped the community epilepsy educator Dianna Sawyer with some of her public speaking engagements.

From the beginning of her service Rosey was to play an incredibly important, indeed a pivotal role in the reinvigoration of the Foundation's engagement with its community . . . people with a lived experience of epilepsy and those who

wished to support them.

When Rosey joined the Foundation her first task was to meet with the women who had kept the opportunity shop operating, against the odds. She also met with the manager of the opportunity shops run by the MS Society and representatives of the St Vincent De Paul Society. Her intention was to learn all that she could about what they did that worked, and to see if the Foundation could learn from their successes and do the same. She succeeded, leading the opportunity shops program into a new era, where they became a profitable and highly valued part of the Foundation's outreach to the community. Rosey took the Foundation from running one opportunity shop to four with a number of paid managers, two vans and some wonderful sponsorships.

Along with Jeremy Maxwell, she also initiated an annual lunch to thank everyone who volunteered their time to work in the op shops. The first of many lunches was hosted by Patron Councillor Philip Brady, and awards were presented to a group of women who'd stuck with the Foundation for a very long time, over two decades years for some . . . many of whom had the lived experience of living with epilepsy in their families, some with SUDEP.

One of the early things Rosey did was to build the number of volunteer public speakers by providing them with the training and support they would need to represent the Foundation in the broader community. The training programs she ran produced a number of outstanding public speakers, and the Foundation also supported their further training as counsellors with accredited training in solution focused counselling. Two of the early trainees, Maree Kearton and Mark Green, eventually joined the Foundation as members of the Client Services staff. Another, Jacqueline Branston

became one of the Foundation's key volunteer speakers and educators.

Rosey also created a role for volunteers in the Epilepsy First Seizure Clinics in major hospitals including St Vincent's, the Royal Melbourne, the Alfred and the Austin. She did this while successfully undertaking a Masters degree in Public Health and then went on to study for a PhD which was in part co-sponsored by the Foundation through Swinburne University.

Rosey and Margot Boyle, the then Client Services Manager, had contacted Jennifer Preston and Jane Hanna, two more remarkable women from the United Kingdom who had lost loved ones with epilepsy to SUDEP. Jennifer, Jane and a number of other women had set up in the UK called Epilepsy Bereaved. They had even managed to have the issue of deaths in epilepsy raised in the House of Commons in an adjournment debate. They were calling for research into the fact that people with epilepsy were clearly dying suddenly, out of the blue, and quite unexpectedly in terms of their general health.

Today sudden, unexplained death in epilepsy, or SUDEP, is being studied around the world and a good deal is becoming known about it, including strategies to deal with it. With Margot Boyle, Rosey also initiated and organised the first biennial memorial service in Australia for those who had lost someone to SUDEP.

In 2005, Rosey along with her friend and colleague, Denis Chapman from Epilepsy Australia, Brendon Moss, and Russell Pollard, took a key role in producing and editing a book called "*Sudden Unexpected Death in Epilepsy: A Global Conversation.*" It contained inputs from 14 nations, giving voice to what both experts and ordinary people with lived experience knew about

SUDEP and looking at the work that needed to be done.

This was a truly groundbreaking book as it clearly demonstrated that the global conversation about SUDEP, and indeed about epilepsy, was one that appropriately engaged people all over the world from both the medical profession and from those engaged in public health including ordinary members of the community with lived experience. It also demonstrated very clearly that many people living with epilepsy wanted to talk openly about the condition with which they were living and they wanted to be engaged in conversations about all aspects of it.

The book was published in print as a continuing global conversation on two further occasions. The second edition was launched at the 29th International Epilepsy Congress in Rome in 2011. The third edition appeared in 2014 and was edited by Jane Hanna, Pauline Brockett, Tamzin Jeffs and Rosey, representing Epilepsy Australia, SUDEP Action in the UK and Canada's SUDEP Aware.

By the time of its third edition, among her various roles, Rosey had become the International Research Officer for the UK's SUDEP Action, which was the new name for Epilepsy Bereaved, and at the 10th Asian and Oceanian Congress held in Singapore in 2014 she told over 1000 delegates that "By working together we can push forward the global conversation on SUDEP which is vital to research and action on SUDEP and epilepsy-related deaths wherever we are in the world." Her contribution continued as an assistant editor of the edition now published on the UK SUDEP Action website.

Rosey also organised dragon boat racing teams involving doctors, nurses, EEG staff from hospitals and epilepsy volunteers, to further raise Epilepsy awareness in Victoria.

So significant have been Rosey's contributions to the Epilepsy Community that she was bestowed in 2011 the Ambassador for Epilepsy Award. This award is one of the most prestigious in the Epilepsy Community, bestowed jointly by the International League Against Epilepsy and the International Bureau for Epilepsy to a limited number of individuals every two years to "proclaim their extraordinary actions advancing the cause of epilepsy, either internationally or with international impact." Rosey is one of only 9 Australians to have received this award in the 50 years since it was first bestowed in 1961, and one of only 2 non-neurologists. In 2016 she won the BMJ community neurology award for The SUDEP and Seizure Safety Checklist.

People who knew Rosey knew that she was a woman of extraordinary energy and commitment. A woman with a first class intellect, a gifted communicator, a warm human being with a broad inclusive smile and a winning sense of humour. She was a very good listener and a sharer of ideas. She

could spend hours engaged in conversations with people about all manner of things. She was what many of us would call a 'polymath'. She was a friend, a mother, a partner, a gardener, a thinker, a counselor, a student, a researcher, a comforter, a colleague who would do whatever it took to accomplish the hardest of tasks. She had her foibles, thank goodness, which let us know that she was also truly human like the rest of us.

In her way too short life she went from Melbourne's University High School into nursing and to horticulture and to public health in the not for profit sector. Her academic accomplishments with Swinburne, Melbourne and Monash Universities while richly deserved were hard won . . . she had to work for them, while raising a family and tending to demanding jobs involving contact with many people across many different communities, all the while that she was studying and learning to become a first class researcher. Rosemary Panelli was one of the remarkable women in epilepsy. She was not only widely respected around the world for her work in public health, where her legacy will live on for many years to come as a part of the story of remarkable women in epilepsy in Australia, she was widely admired as a thinker and activist, and she was truly widely loved. Dr. Rosemary Panelli, Rest in Peace.

● *Article prepared by Pauline Brockett, Maree Kearton, Russell Pollard and Terry O'Brien.*