

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 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.

As a first and important step Rosey set out to get to know every one of the incredible women who ran the op shop. Some of their families had very long connections with the epilepsy movement in Victoria.

Victoria, like many countries overseas, had once had a residential centre which was known as the Talbot Colony and Farm. It had been established for people with intractable seizures long before current medications were available and while it was a world leader in its time it was sadly lost to provide the land required for what is now Monash University. It had been founded in 1907 by public subscription under the guidance of the wife of the Victorian Governor, Lady Margaret Talbot who was a particularly energetic woman and someone who took a very high-profile hands-on role in a range of causes. Margaret Talbot was a woman with vision and determination. The Premier of the day, Sir Thomas Bent, had even quipped that he was "getting frightened of Lady Talbot . . . She is in so many things that are making demands on the Treasury".

In fact, there have been some truly remarkable women who will always be a part of the story of epilepsy in this country . . . and the same can be said for the United Kingdom. Mary Davis who founded the Epilepsy Foundation is one of them. Neuropsychologist Lindsay Vowels who was the foundation President of Epilepsy Australia is another. World renowned neurologist, geneticist and medical researcher Ingrid Scheffer is yet another. Each has been remarkable in their own unique way and of course Rosey Panelli was to well and truly become one as well.

When Rosey joined the Foundation her first task was to meet with the women who had kept the op shop going 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 . . . and a solid source of revenue. 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 [which we'll get to in a moment].

There are many aspects to volunteering that are not widely understood. For instance, it is important not to "exploit" volunteers by burdening them with work that should in the longer term be carried out by paid and appropriately accredited staff, and it's important to offer them real ways to have a voice in what they do in their engagement with an organization.

Rosey was keen to get all of this right. When she learned about a Diploma of Volunteer

Management that was being run from South Australia, and also that it could be undertaken externally in Victoria she asked if the Foundation would support her doing it. And so, she did the course while continuing to work with the Foundation on the days when she was not studying.

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 unexpected deaths. For Jennifer it was her son and for Jane it was her husband. Margot, as the Foundation's Services Manager was helping with the organization of a national epilepsy conference being held in Melbourne, and it was decided that Jennifer Preston who sometimes came to Melbourne to visit family, would come to speak about the charity that she and 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. This was volunteerism at its most powerful.

Jennifer's paper at the conference in Melbourne stirred a great deal of interest, not all of it supportive. Many neurologists knew about the phenomenon of sudden unexpected deaths in epilepsy, and some had made brief references to it over the years. Some neurologists however felt it unwise to "frighten" people with epilepsy with the possibility of this kind of death and really, as a consequence, it was generally not spoken about . . . and so practically nothing was really known about why it happened or how it might be mitigated or prevented. 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, along with her friend and colleague, Denise Chapman from Epilepsy Australia, Brendon Moss, the Foundation's new Metropolitan Services Manager, and Foundation CEO Russell Pollard, Rosey 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 same year that Rosey received a rare honour from the International Bureau for Epilepsy appointing her an "Ambassador for Epilepsy". 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.

Dr Rosey Panelli truly was a major international contributor to the understanding of epilepsy and to SUDEP in particular . . . through her engagement with

countless people living with epilepsy, speaking at Conferences, writing research papers, consulting with worldwide leaders in epilepsy, contributing to the important development of what is known as the SUDEP Checklist . . . and many other activities. Her work even extended to working with general practitioners to help them better understand epilepsy . . . she developed a valued website known as eGP or epilepsy in General Practice.

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.



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A remarkable woman
Rosey Panelli PhD
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