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New South Wales Parliament Legislative Assembly

Palliative Care

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Recently I had the pleasure to meet with two palliative care advocates. Dr Yvonne McMaster, a Senior Australian of the Year finalist and inspiring visionary, spent 20 or more years assisting those facing the final stages of their life to live more comfortably and maintain a quality of life. The other was Mr David Wilkinson, who is the Cancer Council's Blue Mountains member of parliament liaison volunteer and president of the Nepean Blue Mountains Prostate Cancer Support Group.

Both stressed the importance of holistic palliative care to provide the best quality of life possible, up to the point of death. Both were concerned about the inadequacy of existing palliative care services across the State, but in particular, in outer urban and regional areas.

Palliative care aims to provide relief from pain and suffering, and provide care and support to the affected person to enable him or her to live as actively as possible. At the heart of palliative care is a person-centred approach.

Best practice involves multidisciplinary engagement where the team members work with affected persons, their families and carers to achieve a result based on each person's wishes.

Many Australian surveys demonstrate that the majority of people wish to die at home in the presence of their loved ones. Unfortunately, far too many people are denied this opportunity with less than 15 per cent of people in New South Wales able to access the support and care needed to die at home. Recently I received a letter from Margaret following the death of her husband.

She said:

My dear husband Rudolf...passed away whilst in the care of Nepean Hospital in the early hours of 2 June 2016. This was following a short period in hospital as a result of significant respiratory issues that were being treated.

Rudi's death was traumatic, painful and very unpleasant. Not at all like it was described to me earlier that day when it was explained as a decision that would give Rudi (and me) a calm, peaceful death without unnecessary pain or discomfort. My final life memories of Rudi are now of the tortured way he passed from this world, and I deeply regret that his end of life transition was not managed more peacefully, sensitively or respectfully.

His life was not an easy one and he suffered greatly through WWII in concentration camps and later, because of the occupation by the Soviet Union, he spent time as a political prisoner. He was a brave and courageous man who put his own young life on the line for others.

Since news of his death has passed around the world I have received an email box full of tributes to him and a phone full of text messages. His passing would have been easier if his end-stage management had allowed him some dignity in his exit from this life.

Margaret told me, in detail, of the trauma of those final days of hospitalisation. How could Rudi and his family be assisted to endure his final days with dignity and respect? The answer lies, partly, in access to adequate and well-funded palliative care. Far too often we are told that there are no resources to provide the level of care that is required by our aging population.

Yet NSW Health in its report, "Fact of death analysis", shows that on average in the last year of life someone will spend 40 days in hospital at a cost of \$1 billion.

Dr McMaster has been working with her colleague, palliative physician and data analyst, Dr Anthony Ireland, to show how an investment in community-based palliative care would provide net savings for the State and at the same time offer dying people the end-of-life care they are calling for.

New South Wales currently spends 70 per cent of what Victoria does, yet New South Wales is more than three times the geographical size of Victoria. Based on Dr Ireland's calculations, it is estimated that an additional investment of \$27 million per annum is required to meet the current gaps in funding and address the issues of access to services when they are needed. This would net a saving of \$140 million in New South Wales.

At Nepean and Blue Mountains hospitals we have some wonderfully skilled and caring staff in palliative care. Within our community we have incredible volunteers in our Blue Mountains Palliative Support Service. I acknowledge the dedication and professionalism of all these incredible people as they perform such difficult work with the utmost care, compassion and skill. I have spoken to many families in my community who have required assistance from these services, and they speak very highly of these staff and volunteers.

But no amount of care and compassion can fix a system which is overstretched and overburdened. In New South Wales we require an additional 21 palliative positions and four additional trainees. We need an additional 10 specialist palliative care nurses and three more allied health staff per local health district.

People like the late Mr Rudi Werner and his family deserved better in the final stages of his life. We need to equip our health system with the necessary staff and resources to ensure people maintain a good quality of life for as long as possible and, when the time comes, facilitate a peaceful and dignified death.

I thank Dr McMaster for her warmth and intelligence. Her advocacy is passionate, informed, comprehensive and sensible.

I pay my respects to Mrs Margaret Reid-Werner and her family, and I thank her for sharing this most intimate and difficult story with me.