## INQUIRY INTO OFF-PROTOCOL PRESCRIBING OF CHEMOTHERAPY IN NSW

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In 2009, my 87-year-old husband John, was diagnosed with the dreaded asbestos cancer, mesothelioma. At this most terrible of times, he was referred to the wonderful, caring Dr Kiran Phadke. Both John and myself were aware of the terminal nature of his condition and what the next few weeks would mean. Dr Phadke made this time so much easier because we knew Dr Phadke would assess him as a person not a number and use his professional skills and incredible knowledge to provide him with appropriate and responsible treatment in the most compassionate way. The treatment was first class at all times by Dr Phadke and the oncology staff at Sutherland Hospital.

The treatment was age appropriate, patient physical and mental condition appropriate and outcome appropriate. I find it abhorrent that any specialist (let alone a doctor of the calibre and experience of Kiran Phadke) would need to follow dictated protocols EVERY TIME in treating patients as though they were an object!!! How can a "protocol driven" treatment account for the wishes of the patient and their families as well as the mental state of the patient and their families? I hate to imagine John having been forced to follow protocol prescribed treatment when what he really needed was his specialist to discuss alternatives and decide what was best practice for him as an INDIVIDUAL and make his last weeks or months of life (and mine) bearable and functional.

Imagine getting "protocol" treatment but being too mentally and physically scarred to ever benefit from the treatment!!!

Both John and I had complete faith in Dr Phadke and to this day I still most definitely do. Should I ever need to see an oncologist my doctor of choice then and now would definitely be Dr Kiran Phadke.

With regard to protocols and oncology, my daughter in law this year had a stressful and upsetting experience at Sutherland Hospital with her mother. Her mother was in the Emergency Department and needing to be admitted. The only bed available was in Gunyah ward – the oncology ward. Even though the patient, her mother, did not have cancer she was told she could not leave the Emergency Department and be settled into her ward bed and commence treatment for breathing difficulties until a Not For Resuscitation Form had been signed.

Following preset "protocols" the young Emergency Department resident pulled the curtain around the bed (no auditory privacy) and explained the form to the patient, her husband and daughter. The husband was hard of hearing and had reduced cognitive function so he had to speak very loudly meaning everyone around also heard and the husband was totally overwhelmed with the concept and unable to grasp what the resident was meaning. When my daughter in law said can we just get to the ward and then discuss this life defining document calmly with time to think about it, the resident said that he was sorry but it was a preset requirement of Gunyah Ward that this document was signed prior to going there. The system would

not allow admission to the ward without it. They therefore had about 2 minutes in an emotional overwhelmed state in an Emergency Department to discuss and decide what to do before signing a form that may end her mother's life if enacted. How can that be best practice oncology in 2016?

I urge you to let highly trained and experienced specialist oncologists use their skills to provide every INDIVIDUAL oncology patient with treatment that caters to their physical, and emotional needs in a caring and compassionate way without fearing repercussions from a hierarchy hell bent on dictating what, when and how treatment will occur.

Clearly protocol prescribing of treatment does not work and patients will suffer.

Daphne Patterson, Caringbah